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Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME I

Herbert Leibowitz	RESEARCH AND TRAINING SPECIALIST FOR THE REHABILITATION SERVICES ADMINISTRATION, 1971- 1990
Mary Lester	GRANT WRITER FOR THE EARLY CENTER FOR INDEPENDENT LIVING IN BERKELEY, 1974-1981
Bette McMuldren	ASSISTANT TO JUDY HEUMANN AND GRANT WRITER AT THE CENTER FOR INDEPENDENT LIVING, 1975-1980
Kenneth Stein	PUBLIC INFORMATION COORDINATOR FOR THE CENTER FOR INDEPENDENT LIVING AND PARTICIPANT/OBSERVER OF THE DISABILITY MOVEMENT

Interviews Conducted by
Sharon Bonney
Susan O'Hara
and Jonathan Young
1998

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TABLE OF CONTENTS--Builders and Sustainers of the Independent Living
Movement in Berkeley, Volume I

SERIES INTRODUCTION by Simi Linton	i
SERIES HISTORY by Ann Lage and Susan O'Hara	vii
SERIES LIST	xiv
INTERVIEW WITH HERBERT LEIBOWITZ <i>Research and Training Specialist for the Rehabilitation Services Administration, 1971-1990</i>	xix
Table of Contents	xx
INTERVIEW WITH MARY LESTER <i>Grant Writer for the Early Center for Independent Living in Berkeley, 1974-1981</i>	30
Table of Contents	31
INTERVIEW WITH BETTE MCMULDREN <i>Assistant to Judy Heumann and Grant Writer at the Center for Independent Living, 1975-1980</i>	119
Table of Contents	120
INTERVIEW WITH KENNETH STEIN <i>Public Information Coordinator for the Center for Independent Living and Participant/Observer of the Disability Movement</i>	168
Table of Contents	169
TAPE GUIDE	215
INDEX	216

SERIES INTRODUCTION--The Disability Rights and Independent Living Movement, by Simi Linton

When I was asked to write the introduction to the Bancroft Library's oral histories on the disability rights movement in Berkeley, it reminded me of the summer of 1975, when I left New York City and headed out to Berkeley, California. For Berkeley was the place to be I told my friends, filled with hippies and free love. I would spend the summer, take courses at the university. I had been disabled just a few years and this was my first trip on my own, away from the tight circle of family and friends I had relied on in those early years.

Someone had told me that Berkeley was a center of disability activism, but I didn't tally that in my list of reasons to go there. I was a naive young woman in my twenties, and still new to disability. I "managed" my disability by keeping its profile low, and its needs in check. I use a wheelchair, and did then, and decided I would need to call the disabled students' office at the university to get help finding an accessible apartment near the campus, but also decided this would be the only concession I would make to my disabled state. I was fine, I told myself and my family, and by that I meant I could go anywhere, I could do everything. Disability would not bog me down and it would not mark me.

While bold on the outside, I harbored the deep fear that I might fail in my ability to keep disability in its place, that it would come crashing in around me and swallow me up. I, therefore, was completely unprepared for the headlong leap I made that summer toward disability, toward the people and the territory that I had shunned. I never imagined that I would move toward disability with interest and gusto. It didn't happen all at once in that brief summer, but I call that time in Berkeley my coming out.

I had arrived in a place where disability seemed more ordinary than it was where I had come from, where accommodations were apparent, where the curbcuts on every corner made it possible for me to go to the supermarket, to the bookstore and up to campus without having to stop someone at each corner, explain to them how to tilt my wheelchair back, take it down the curb, and lift it back up on the other side. Although Berkeley may not have had significantly more disabled people than other places, it seemed to. Maybe it was because I was out on the streets more than I was in New York. I saw people acting out the daily routines of life--going to the supermarket, school or their jobs--using wheelchairs or crutches, brandishing white canes, using sign language and all of the other indicators of membership.

And life started to become easier and more flavorful, not by avoiding disability but by living with it in a different way. The lure of the other disabled people I saw was great, and I learned that it was those people, most I never got to meet, who were responsible for the curb cuts, accessible bathrooms, the independent living center where I went for help, and the disabled students office that had found an apartment for me. I had never seen any place where disabled people were in charge and it thrilled me and made me optimistic about my life in a way that no other experience could.

I learned back then that it was not some benevolent church group that carved out those curb cuts, or a member of the town council trying to get votes who mandated accessible facilities, they were due to the deliberate actions and painstaking labor of members of the disability community who fought for the changes that were made. Their work set the stage for the ongoing struggle for rights and liberties that has engaged a nation of activists. Today, while discrimination remains a constant in disabled people's lives, the right to an accessible environment, to housing, employment, and transportation is governed by laws that are increasingly exerting influence on those who discriminate. Further, the idea of integration, in education, in public accommodations and in transportation, pervades the informed discourse on disability rights and is supported, again, by legislation that mandates desegregating society.

The Bancroft Library's Regional Oral History Office project, "The Disability Rights and Independent Living Movement: The Formative Years in Berkeley, California, 1960s-1980s," exposes the brick and mortar of these victories. Present in the narratives are major players and significant events, as well as the vital auxiliary figures and contributing influences that form the connective tissue of the Berkeley portion of these movements. The histories also reveal the dilemmas and roadblocks that halted progress and interfered with the integrated and equitable society that the framers of this political agenda envisioned.

It is a critical time to look closely at the progress that has occurred, and to study the impairments and deficits that remain in our not yet fully integrated and equitable society. Researchers, activists and those who write policy need, of course, to examine the present moment, and evaluate the necessary steps to take to move forward. Yet, just as important, is an examination of what led us here. How are present problems connected to past struggles? How do ideas that we act on today, relate to those formulated in past eras?

The oral history project provides detailed answers to those research questions. The material they have assembled will be of value to researchers, artists of all kinds, activists and policy makers. This endeavor is made possible now by opportunities afforded by the present moment that were not readily available before. The early activities and ideas have had the opportunity to grow and take root. There has been

time to evaluate their impact and to see the shifts in ideas, policy, and human interactions spurred by what at first glance might seem to be a random set of activities undertaken in reaction to specific concrete problems.

In addition, there have been a number of developments over the last three decades that have created both the need and the impetus for this work. I've grouped these into four sections that outline some of the cultural, scholarly and political activity that informs this work.

The Social Construction of Disability and the Significance of Community

What I witnessed in the summer of 1975 when I came to Berkeley from New York was that disability could mean something different just by moving to a new location. I wouldn't learn the term "social construction" for another fifteen years, but I did learn through direct experience that disability is not fixed. I also learned that the disability community is a powerful and meaningful entity.

Fundamental to the Regional Oral History Office project is an understanding of the social construction of disability. The efforts begun in the sixties by the people interviewed here to reframe disability as a social designation and to conceptualize obstacles to employment, education and integrated living as a civil rights issue, rather than an individual problem of impairments and deficits, made it possible to understand disability that way. Further, an essential prerequisite for the progress of the disability rights movement was the organization of the disability community, a coalition formed by the discovery of each other and the recognition of our common social status. Although medical and educational institutions continue to categorize and divide people by impairment status, the formation and the formulation of the "disability community" has had a major impact in the social/political arena.

For all my early learning, and my ongoing study of disability, it is in reading these histories that I have begun to understand how profound and original the ideas are that drove the early activists. The voices that are heard here demonstrate the purposefulness of the activists and their comprehensive vision of an equitable society. If this research platform were to reveal nothing else, it would be invaluable as a means to contradict the stereotypes of disabled people, and of the disability rights movement as merely riding the coattails and mimicking the agendas of the civil rights and feminist movements.

Yet, not only does this collection of histories serve as an exemplar of social construction and the significance of community, it demonstrates the unique nature of the construction of disability and illustrates the struggle to define and assert rights as a minority group

in the face of powerful efforts to confine disability within the province of medical discourse.

The Value of First-Person Narratives

A second domain that informs this project is the increased attention to the active voice of previously marginalized peoples. First person narratives, long discredited in academic circles, are now accepted by a wide variety of scholars and public historians as not only valid, but necessary research tools. ROHO's intent to bring disabled people's perspective to the forefront is consistent with that approach, and the nuanced and detailed data they obtained demonstrates again the value of the methodology. Disability has traditionally been studied as the effect of war or violence, the failures of medicine, or other causes. In these narratives, we see that what brought disability to the individual becomes much less important than what the presence of disability causes to happen. Significantly, the narrators show the ways that disability sets in motion certain social and institutional responses. As these histories reveal, a disabled person's presence in a school, a restaurant, a job interview, a social gathering, or other venue often caused events to unfold in particular ways.

While scholars outside of disability studies have rarely paid attention to disability narratives, this project provides compelling documentation of the place of disability within the larger social arena, and also demonstrates the ways that disability plays a role in shaping an historic moment. I believe that the rich insights of the narrators and their ability to reveal the complex consequences of disability oppression will engage scholars within disability studies as well as those outside the field. For instance, researchers might want to look at what the histories reveal about the parallels between the place of women in other early civil rights struggles and in the disability rights movement. They may want to examine disabled people's perspective on their exclusion from other social justice platforms or consider the obstacles that the disability community itself may have erected to coalition building with other disenfranchised groups.

Complex Representations of Disability and the Social Milieu

The oral histories provide detailed descriptions of the lives of the narrators and others in their circles. These materials will be useful not only to researchers and activists but to writers and artists interested in portraying the lives of the people interviewed, or developing fictional representations using these figures as stimuli. For instance, writers can turn to these histories for background information for projects that dramatize events of the sixties. The projects might relate specifically to the events or the people described in the oral histories, or the research might be aimed at gaining more accurate information about secondary characters or events. A writer

might want to learn more about what the Cowell Residence really looked like, who lived there, what were the attendants like, some of whom were conscientious objectors doing alternative service during the Vietnam War, or what kinds of wheelchairs and other adaptive equipment were people using then. These histories are about disabled people and the genesis of the disability rights movement, but they are also histories of the period and will be useful in providing more accurate representations of both.

While mainstream cultural products continue to depict disabled people and disabled characters in inaccurate and narrow ways, a growing number of writers, artists, actors, and performance artists who are disabled or are insiders in the disability community are providing more realistic, interesting and complex representations of disability to a wider audience than the arts ever have before. Although the numbers are still small and the venues marginal, I expect that over the next decade, as increasing numbers of disabled people gain access to higher education and training in the arts, their ranks will grow and as they do, this material will continue to grow in value.

A Resource for Disability Studies Scholars

Finally, this project will be an invaluable resource to the growing ranks of disability studies scholars. Disability studies began to take shape as an organized area of inquiry in the early 1980s. Prior to that time, although there were isolated pockets of transformative scholarship in some liberal arts fields, the study of disability was housed almost exclusively in the specialized applied fields (rehabilitation, special education, health, et cetera). Disability studies came along and provided a place to organize and circumscribe a knowledge base that explains the social and political nature of the ascribed category, disability. The field has grown enormously, particularly since the early 1990s, as has the Society for Disability Studies, the organization that supports the work of scholars and activists interested in the development of new approaches that can be used to understand disability as a social, political and cultural phenomenon.

Certain ideas pervade disability studies. For instance, a number of authors have examined such ideas as autonomy and independence. The perspectives employed in a disability studies analysis of such phenomena afford a complex look at these hitherto rarely examined ideas. Scholars interested in the theoretical implications of these ideas will benefit from examining the ROHO histories. They will learn, as I did in a recent reading, how the early activists discovered that the surest route to gaining independence was to have access to attendant care. These young people, many just out of institutions, or living away from home for the first time in their lives, were creating a new type of community, one in which it was clearly understood that support and

services are necessary for individual autonomous functioning. They recognized the irony that what is typically thought of as "total dependence" was instead the ticket to the greatest freedom and autonomy they'd ever known. Rather than wait for the nurse or orderly in their institution to "decide" if it was time to get out of bed, have a shower, eat dinner or watch television, with personal attendants available and under their direction they could make these decisions on their own. Rather than wait at home for their mother or other relative or friend to bring them food or take them somewhere, they could lobby the university for a lift-equipped van that would be at their disposal and provide them with access to the kinds of leisure activities non-disabled students take for granted. They learned by setting up their own wheelchair repair services, and hiring qualified mechanics, they could keep their manual chairs, and the power wheelchairs that they also had lobbied for, in working order.

Through their lived experience they had the occasion to formulate a new way of thinking about such accepted ideas as what constitutes independence; what is freedom, equity, and integration; the ways that physical dependence and psychological independence are two separate and potentially unrelated variables. Disability studies, while dominated by theoretical formulations, social science research methodology, and modes of analysis employed in various areas of the humanities, will benefit enormously from the concrete examples given here of the abstract principles our work depends on.

The value of this project will ultimately be revealed as future research, creative endeavors, and policy initiatives are developed that have utilized this primary source material. Over the decades to come, researchers in all areas of inquiry will find within these documents numerous variables to be tested, relationships among people, events, and trends to be examined, cultural phenomena to be studied and dramatized, and ideas to be woven into theory or literature. The most exciting research opportunity that this work affords is the examination of the beliefs and behaviors of people whose demands for equity and justice upped the ante in the fight for an inclusive society.

The Regional Oral History Office staff are to be commended for their vision. They have brought us a vital piece of history, one that would be lost and forgotten if it were not for them. They have captured in these individual histories, a history. And a legacy.

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New York, New York
April 1999

SERIES HISTORY--The Disability Rights and Independent Living Movement
Oral History Project, by Ann Lage and Susan O'Hara

Historical Framework

The movement by persons with disabilities for legally defined civil rights and control over their own lives took on its present framework in the 1960s and 1970s. Virtually simultaneously in several cities nationwide, small groups of people with significant disabilities joined together to change the rules of living with a disability. No longer content with limited life opportunities, nor willing to be defined solely as medical patients, they shared the willingness to challenge authority, discard received wisdom, and effect societal change that was the hallmark of the era. Not surprisingly, the disability movement paralleled other movements for equity and civil rights by and for racial minorities, women, and gay people. From our vantage at the close of the century, it is apparent that these movements, taken together, have changed the social, cultural, and legal landscape of the nation.

Berkeley, California, was one of the key cities where models for independent living were developed. A small group of young people, all wheelchair users, had one by one enrolled at the University of California in the 1960s. In an era prior to accessible dormitories or private housing, they were given living quarters in the campus's Cowell Hospital. In the midst of the campus maelstrom of free speech, civil rights, and anti-war protests, they experimented with radical changes in their daily lives, articulated a new philosophy of independence, and raised their experience to a political cause on campus and in the community.

By 1972, these students had created new institutions, run by and for people with disabilities, which soon attracted national attention. The first two of these organizations, the Physically Disabled Students' Program on the campus and the Center for Independent Living in the community, drew several hundred people with disabilities to Berkeley from across the United States. This early migration became the nucleus and the strength of the community that, for many, came to symbolize the independent living movement.

Political action kept pace with the developing awareness and institutional growth. In the early seventies, the Berkeley group successfully lobbied the city of Berkeley for curb cuts and the state legislature for attendant care funding. In 1977, scores of persons with disabilities sat in for twenty-six days at the offices of the federal Department of Health, Education, and Welfare in San Francisco, as part of a nationwide protest that eventually forced implementation of Section

504 of the Rehabilitation Act of 1973, often called the Bill of Rights for Americans with Disabilities. Many participants trace their awareness of disability as a civil rights issue and their sense of membership in a disability community to the 1977 sit-in.

By the 1980s, a number of other important organizations had evolved from the Berkeley experience: the Disability Rights Education and Defense Fund (DREDF), the World Institute on Disability (WID), Computer Training Program (later, the Computer Technologies Program [CTP]), the Bay Area Outreach Recreation Program (BORP), and others. All of these organizations shared the original philosophy of the Berkeley movement. Their example and their leaders have had national and even international impact on the quality of life and civil rights of persons with disabilities.

Genesis of the Project

The idea for a project to document these historic events germinated for nearly fifteen years before funding was secured to make possible the current effort. In 1982, Susan O'Hara, then director of the Disabled Students' Residence Program at the University of California, Berkeley, contacted Willa Baum, director of the Regional Oral History Office (ROHO) of The Bancroft Library, suggesting that the genesis of the Berkeley movement be recorded in oral histories with participants in the campus's Cowell Hospital Residence Program. Mrs. Baum and Ms. O'Hara began planning, enlarged the project scope, gathered faculty support, and initiated the search for funding. Their efforts produced three grant applications, the final one in cooperation with Professor Raymond Lifchez of the UC College of Environmental Design, to the National Endowment for the Humanities, none successful.

ROHO then secured funding from the Prytanean Society, a Berkeley campus women's service group, to produce oral histories with Arleigh Williams and Betty Neely, both campus administrators who oversaw the establishment of the early disabled students' programs. Herb Wiseman, a former staff member of the disabled students' program, conducted these two interviews in 1984-1985. Later, the California State Archives State Government Oral History Project funded an oral history with Edward Roberts, the first student in the Cowell program and later the director of the California State Department of Rehabilitation. This initial support proved essential; all three individuals were to die before the current project was funded.

By 1995, as the historical importance of the events in Berkeley and beyond grew increasingly evident, the fragility of the historical record became ever more apparent. The archival records of key institutions that grew out of the movement and shaped nationwide events were not collected and preserved in a publicly accessible library. The

personal papers of key leaders of the movement were scattered in basements and attics. Moreover, the urgency of preserving the memories of participants through oral history interviews was underscored by the death of five pioneer disabled activists in the previous several years.

When Susan O'Hara and Mary Lou Breslin outlined the scope of the problem to The Bancroft Library, the then-curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum in support of the idea of developing a comprehensive disability collection at Bancroft. Baum, Hardwick, and Ann Lage, associate director of ROHO, worked with leaders of the disability community to design a plan for an archival collection at The Bancroft Library, to include both in-depth oral history interviews and written and photographic records of major organizations and activists. The Disabled Persons' Independence Movement collection was envisioned as "a primary historical resource of national significance, a research platform for future scholars, for persons with disabilities, and for public education." The National Institute on Disability and Rehabilitation Research generously funded the three-year project in 1996.

Project Staff and Advisors

The collaborative nature of the project--among the disability community, academic advisors, oral historians, and archivists--has strengthened it in every respect. The advisory board included three Berkeley professors: Frederick Collignon of the Department of City and Regional Planning, who has worked on disability issues since 1970; Raymond Lifchez, Department of Architecture, who has conducted research on environmental design for independent living since 1972; and William K. Muir, Department of Political Science, who has chaired campus committees on disability issues, and is a scholar of U.S. and state government and public policy. Paul Longmore, professor of history from San Francisco State University and a specialist in disability history, was crucial in defining themes and topics to explore in oral history interviews. Mary Lou Breslin, president and co-founder of the Disability Rights Education and Defense Fund, represented the perspective of the organizations to be documented as well as her personal experiences as an activist for disability rights.

Knowing that oral history is most often successfully carried out by persons who combine a compelling personal interest in the project with an ability to bring a historical perspective to their task, the Regional Oral History Office turned to the Bay Area disability community itself to staff the project's team of interviewers. Susan O'Hara became the historical consultant for the project and conducted a number of interviews as well as informing all of the project activities. All of the project interviewers had personal experience with disability. A majority had significant disabilities, several had participated in or

observed the historical events to be documented and knew many of the key players and organizations. Interviewers included Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, who crossed over from the advisory board; Kathy Cowan, librarian for a public-interest nonprofit organization; Denise Sherer Jacobson, a writer and educator on disability issues; David Landes, a college instructor of economics and coordinator of student affairs for the Computer Technologies Program.

Joining the team to interview narrators in Washington, D.C., was Jonathan Young, a Ph.D. candidate in American history at the University of North Carolina who had conducted oral histories on the history of the Americans with Disabilities Act. When Mr. Young resigned to accept a White House appointment, Susan Brown, long familiar with disability issues and other civil rights/social movements, became the project's Washington connection. Ann Lage coordinated the interviewing team for the Regional Oral History Office, and the office's regular staff, coordinated by production manager Shannon Page, provided transcription and other clerical support.

Bancroft Library project personnel included Bonnie Hardwick, curator; Lauren Lassleben, supervising archivist; and Jane Bassett, the project archivist whose job it was to contact the disability organizations, project interviewees, and other activists and survey their records to identify historical material. Once records and personal papers were donated to the Library--more than 300 linear feet before the project's conclusion--it was Jane and her student assistant, Amber Smock, who preserved, organized, and made the papers accessible to scholars with detailed finding aids. The archival and oral history projects, though separately administered, were in close cooperation, with the interviewing team providing contacts with the disability community and leads on papers to collect and the archivists assisting interviewers in their research in the growing collection of written records.

Interviewees and Themes

An overarching question for the project was to explore and document how this social movement developed in time, place, and context: how the movement in Berkeley was built, how it became effective, how individual life experiences contributed to and were changed by the movement. Lines of inquiry included identity issues and personal life experiences; social/economic/political backgrounds of individual activists; the roles of women and minorities in the movement; development of leadership; institution building and management; development of a disability community group identity; media, mythology, public image and the political process; impact of technology; the range

of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Interviewees (narrators) were selected for one of several reasons: the individual was a founder or recognized leader of one of the key institutions, made a unique contribution to the movement, was a particularly keen observer and articulate reporter, or was a sustainer of the movement who provided a unique perspective. We attempted to choose narrators who had a range of disabilities and to interview nondisabled persons who contributed significantly to events or institutions.

Interviewees fell primarily into two categories: either they were involved in the residence program of Cowell Hospital on the Berkeley campus in the sixties or they participated in the building of early organizations in the 1970s.

Group One--UC Berkeley's Cowell Hospital Residence Program

A wing on the third floor of Cowell Hospital was the site of the first housing for students with significant disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students--mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp--spent several years in this benign but nonetheless isolated hospital residence, in the middle of a campus exploding with student protest movements. Six of these students were interviewed, including Ed Roberts, who narrated several hours of 1960s memories before he died with the oral history still in process. The former students all refer to their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

Also included in this first group were certain early university and State Department of Rehabilitation officials--the hospital director, the nurse/coordinator, counselors--who might be called traditional gatekeepers but nonetheless allowed the unorthodox residence program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities, overlapping with the events documented in the second group of narrators.

Group Two--Builders of the Movement

The second group of interviewees are primarily founders and leaders who participated in the expansive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the university, followed by the founding of the Center for Independent Living (CIL) in 1972. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause", seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. In the next few years a whole constellation of organizations evolved to sustain the independent living movement, including DREDF, CTP, KIDS, BORP, WID, Center for Accessible Technology (CAT), and Through the Looking Glass. This group of interviewees provide insight into the politics, leadership, and organization-building of both their own organizations and CIL.

Many key interviewees in this group are still in leadership positions and have had national and international impact on disability policy development. Also included in this second group are persons who were not in the top ranks of leadership but who were keen observers of the scene, could augment the basic history, and offer further points of view.

Oral History Process

All of the project interviewers received formal and informal training in archival oral history procedures and met monthly as a group to plan and evaluate interviews and review progress. Interviewers prepared a preliminary outline before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. In-depth tape-recorded interview sessions were from one to two hours in length; interviewees required from one to fifteen sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and give additional information when needed. The final stage added subject headings, a table of contents, and an index. Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs.

More than forty oral histories are included in this first phase of the Disabled Persons' Independent Movement project. Volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to

other libraries and to individuals for cost of printing and binding. Many of the oral histories are accompanied by a videotaped interview session to document visual elements of the interview and the setting in which the interviewee lives or works. Video and audiotapes are available at The Bancroft Library. If funding for a second phase of the project is secured, many of the oral history transcripts as well as a representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at <http://library.berkeley.edu/BANC/ROHO/>.

Special thanks are due to donors to this effort over the years: the Prytanean Society; Raymond Lifchez and Judith Stronach; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project. The Bancroft Library's three-year Disabled Persons' Independence Movement Project, of which these oral histories are a part, was funded by a field-initiated research grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Ann Lage, Project Coordinator
Susan O'Hara, Historical Consultant

Regional Oral History Office
The Bancroft Library
University of California, Berkeley
September 1999

August 2000

Disability Rights and Independent Living Movement Oral History Series
The Formative Years in Berkeley, California

Single-interview volumes

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Joel Bryan, *Founder and Director of Disabled Students' Services, UC Riverside and UC Davis, 2000.*

Kitty Cone, *Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977, 2000.*

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Arlene Mayerson, Directing attorney, Disability Rights Education and Defense Fund. (in process)

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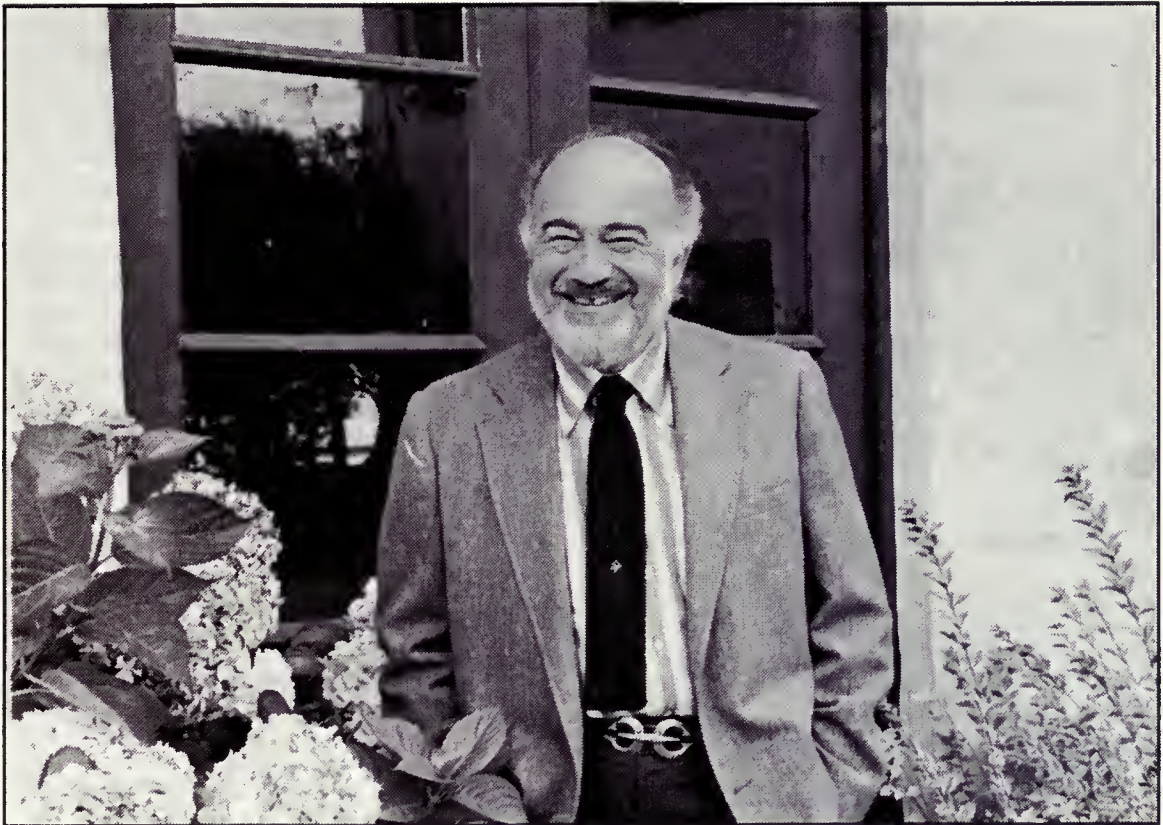
Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME I

Herbert Leibowitz

RESEARCH AND TRAINING SPECIALIST FOR THE
REHABILITATION SERVICES ADMINISTRATION, 1971-1990

An Interview Conducted by
Susan O'Hara
in
1998



Herbert Leibowitz at UCSF, circa 1980.

Photo by Dr. Leonard Green.

TABLE OF CONTENTS--Herbert Leibowitz

INTERVIEW HISTORY	xxi
BIOGRAPHICAL INFORMATION	xxii
Background Years: From New York to Berkeley, 1923-1971	1
Los Angeles Youth Project, 1946: Area Supervisor	1
Columbia University, 1953: Introduction to Rehabilitation at Guidance Laboratory	3
Gallup Indian Community Center, 1956: First Direct Rehabilitation Work	4
National Federation of Settlements, 1959: Personnel Director	7
Social Welfare Extension at UC Berkeley, 1963-1969: Director	9
Peace Corps in Bombay, India, 1969-1971: Regional Director	11
Rehabilitation Services Administration [RSA], 1971-1990: Research and Training Specialist	11
The First Call from Disabled Students at UC Berkeley, 1971	13
The Independent Living Concept and Rehabilitation Services Administration	15
National Conference on Independent Living, Berkeley, 1975	18
RSA Grants to Center for Independent Living: Peer Counseling, Wheelchair Development	21
Reflections on Ed Roberts and Judy Heumann	24
World Institute on Disability, 1990-1996: Research and Training Center, and AIDS Project	28

INTERVIEW HISTORY--Herbert Leibowitz

Herbert Leibowitz was invited to participate in the Disability Rights and Independent Living Movement Oral History Series because of his role in the Rehabilitation Services Administration [RSA], the federal agency charged with implementing the Rehabilitation Act, enacted in 1920 and reauthorized to the present day.

As a research and training specialist based in San Francisco, Leibowitz orchestrated the first grants from RSA to the fledgling Center for Independent Living in Berkeley in the early 1970s. His support of the independent living movement stood in sharp contrast to the traditional stance of RSA, which had yet to recognize the concept of control by clients/consumers in decisions affecting their own lives. Having worked in the pursuit of social justice since 1946, Leibowitz innately understood the significance of the new movement, and indeed helped the CIL to host a national conference on independent living in 1975. Not disabled himself, he was nonetheless at ease with the local movement leaders; he describes his observations of Ed Roberts, Judy Heumann, and John Hessler in the interview. The final part of his interview recounts his years (1990-96) at the World Institute on Disability, founded by Roberts, Heumann, and Joan Leon.

The interview was recorded at the home of the interviewer in Berkeley in November, 1998. Leibowitz reviewed the transcript and made no significant changes. He and the interviewer had been acquainted for several years.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Susan O'Hara
Interviewer-Editor

January 6, 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name HERBERT H. LEIBOWITZ

Date of birth 1/10/23 Birthplace New York City

Father's full name ABRAHAM LEIBOWITZ

Occupation Tailor Birthplace Romania

Mother's full name ANNA KUTCHOWITZ

Occupation _____ Birthplace Poland

Your spouse Marian

Occupation Elementary School Counselor Birthplace Pittsburgh, Pa.

Your children David - M.D. - Kaiser Perm.

Mark - Ph.D. - Bio-Physics

Where did you grow up? New York City

Present community Berkeley

Education BA - NYU; MSW - U.S.C.

Ed.D. - Columbia / Teachers College

Occupation(s) social worker - community work.

Program Development

Areas of expertise community organization;

creative programming.

Other interests or activities arts, music

Organizations in which you are active _____

INTERVIEW WITH HERBERT LEIBOWITZ

Background Years: From New York to Berkeley, 1923-1971

[Date of Interview: November 17, 1998] ##¹

O'Hara: Herb, could you start with giving us just a little bit of your background? Where were you born and when?

Leibowitz: Okay. Herb Leibowitz was born in Brooklyn, New York, January 10, 1923. I lived in Brooklyn until I was twenty-one years old, in 1944. I had gone through the public schools. I went to New York University and Washington Square College from '40 to '44. When I graduated NYU [New York University] I went to the graduate school of social work at the University of Pittsburgh.

O'Hara: What was your undergraduate work in?

Leibowitz: My major was a program known as pre-professional social work. It was essentially sociology, and I had a minor in philosophy and other things. I enjoyed my work at NYU.

Los Angeles Youth Project, 1946: Area Supervisor

O'Hara: Did you get a job right after your graduate work?

Leibowitz: Yes. Well, I was at Pitt [Pittsburgh] for a year and a half, and then I went into the army. I was in the army for almost two years, and during that period I got married to Mickey, who was at that point living in California. When I got out of the army in 1946, Mickey and I settled in Los Angeles, and my first

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

job was with the Los Angeles Youth Project, which was an organization developed after what are known as the Zoot Suit Riots. Does that mean anything to you?

O'Hara: No. What were they?

Leibowitz: That was during the Second World War. At one point--I think it was probably 1944 and 1945--a group of marines in downtown Los Angeles on leave got involved in a fight with what were called zoot suiters. They were mostly Hispanic kids, I think, and they used to wear the zoot suit outfits, long jackets and stuff.

O'Hara: Can you describe the zoot suit for future historians just a little bit more? Were they a certain color?

Leibowitz: No, I think they came in all different colors, but the young people would spangle them. It was essentially--some studies were done later--an attempt by these young people to really have a uniform. This was during the war, this was when most men were in uniform--army, navy, marines.

O'Hara: Was the youth project then founded for the zoot suit crowd?

Leibowitz: Basically, yes. After the riots they did a big study of youth services in Los Angeles County and they found that 90 percent of youth services were going to middle-class kids: the scouts, the Protestant church agencies, the Catholic Youth Organization, the Jewish centers, Woodcraft Rangers. They were not really serving what were defined as less-chance areas where poor kids and minorities lived. So this was the first time this had really been underlined, the question was raised by the Community Chest youth-serving agencies: "Why aren't we serving these kids?" The Los Angeles Youth Project was developed, and it defined ten "less-chance" areas. The areas in the city of Los Angeles going from Watts and Willowbrook in the south, up through central Los Angeles and over to the east side to the Boyle Heights and the Chicano neighborhoods--the ten youth project areas where kids were not being served. It was a wonderful agency and I was very lucky to--

O'Hara: What did you do?

Leibowitz: I was known as an area coordinator. It was really a community organization job. I worked in Watts and Willowbrook, in the Florence and Firestone neighborhoods.

O'Hara: When you say community organizing, who were you organizing?

Leibowitz: I was working essentially with the youth serving agencies to help them expand their work with kids in these neighborhoods where services were not available. The job of community organization involved working right in the community with the neighborhoods, with the families, with the schools, the churches, the youth organizations, to look at the question of what's needed to serve these young people. I think it was probably the best job I ever had.

O'Hara: What attracted you to it in the first place?

Leibowitz: I did some field work with the youth project while I was finishing my graduate work at USC [University of Southern California]. The job was available. Actually, I'll tell you a funny story about it. I was offered the job as the area coordinator, and then John Pixley, the man who had hired me, called me and said, "Herb, I'm sorry. I offered you the job, but my boss, Whit Pfeiffer, says I can't hire you because you're too young." At that point I was twenty-three or twenty-four, and Pfeiffer was kind of an old conservative social worker. He said, "Oh, we can't hire a man less than thirty-five years old for this job."

At any rate, John Pixley, who was a great guy, wouldn't give up, and he finally came to me and said, "Look, I've got Pfeiffer to hire you if you'll accept less salary for six months to prove yourself." So I did it. Of course, it all worked out. It was a wonderful job.

O'Hara: How long did you stay there?

Leibowitz: About four years. Our first son, David, was born in 1949, and then in 1953 Mickey and I left Los Angeles.

Columbia University, 1953: Introduction to Rehabilitation at Guidance Laboratory

Leibowitz: I went back to Columbia University to work on my doctorate. There again I had a very interesting job as intake supervisor in the guidance laboratory. That's when I had my first introduction to rehabilitation work.

O'Hara: And what was that like?

Leibowitz: As the intake supervisor at the guidance laboratory I did the intake process for all of the potential clients who came in to

see counselors from the various divisions of the [Columbia University] Teachers College.

O'Hara: Is the guidance laboratory part of the Teachers College?

Leibowitz: Yes. It was one of the first university-based guidance centers.

O'Hara: And it was for young kids.

Leibowitz: And adults. Parents came in with kids who needed remedial reading help--a whole range of possible assistance. What I did as intake supervisor was see the parents and the kids first and do an intake interview and evaluate whether the individual could benefit from the services we had, because these were graduate students who were doing the counseling under supervision of faculty people and with clinical psychologists, counseling psychologists, and that was the thing that was closest to the rehabilitation counseling field. Abe Jacobs, Al Thompson--these were guys who were early academics in the vocational rehabilitation counseling field.

O'Hara: I see. Now was the Teachers College part of Columbia?

Leibowitz: Yes.

O'Hara: Some clients had some form of disability?

Leibowitz: Yes. Many of the people who came in had some level of disability and were concerned about job development, psychological counseling. It was a very exciting and interesting piece of work, and I was there for almost four years.

Gallup Indian Community Center, 1956: First Direct Rehabilitation Work

Leibowitz: Then Mickey and I moved to Gallup, New Mexico, with the Gallup Indian Community Center, which was a Unitarian service committee project working with the Navajo Indians and the Zunis.

O'Hara: Doing?

Leibowitz: Doing a wide range of work. For one thing, we had a building in Gallup that was the Indian Center. It was a new building

that had been built by the Bureau of Indian Affairs [BIA] and the Navajo Tribe and McKinley County. It was a very dramatic development, because although Gallup was known "as the Indian capital of the world," there wasn't any place in Gallup where an Indian could go to the bathroom, or was welcome at a motel.

O'Hara: Oh, it was not allowed.

Leibowitz: Not that there was a law against it [chuckles], but they were psychologically not allowed. The only thing they were allowed to do was come in and buy the cheap wine; they used to come into Gallup by the carloads. It was a very, very sad state of affairs, and it had been that way for many, many years.

O'Hara: So you had a complete mix of needs among this clientele.

Leibowitz: Right. And our job at the Indian Center--because it was sponsored by the Navajo Tribe and the BIA and the county of McKinley--was, again, to try to do an individual job with people who came in with problems, et cetera. We had an Indian health service clinic in the building. We had rooms that we rented overnight for a dollar. We had showers and bathrooms and counselors for people who came in with problems.

O'Hara: By this stage in your career what were you thinking of in rehabilitation?

Leibowitz: Well, let me give you a specific example. One of the things I had gotten involved with in Gallup was rehabilitation of Indian alcoholics. That was and still remains a tremendous problem with American Indians. One of the things that struck us the minute we got to Gallup was that there were men, women, and children just completely plastered on cheap wine. You were always reading about the drunken Indians in Gallup. The train went through, and you'd always see these hordes of very sad, very sick-looking men and women.

O'Hara: Was it commonly thought of in those days to see alcoholism as a disease, as a rehabilitation issue?

Leibowitz: It was in New Mexico.

O'Hara: It wasn't news to you to treat it as a rehabilitation type issue.

Leibowitz: Right. It was very interesting, one of my first contacts was with the New Mexico Commission on Alcoholism. The guy who was the director of that commission--his name was Bob Hoover--was an ex-alcoholic, and they ran two rehabilitation centers. One

was known as Turquoise Lodge, and then there was another one down in Roswell. Turquoise was in Albuquerque.

O'Hara: Is that the same Bob Hoover that became a friend of Ed Roberts up here?

Leibowitz: I don't think so.

O'Hara: From the College of San Mateo or--

Leibowitz: No.

O'Hara: A different one.

Leibowitz: Yes.

O'Hara: A black man?

Leibowitz: No.

O'Hara: Okay, not the same.

Leibowitz: At any rate, when I got involved and concerned about the alcoholism question, step number one was what can you do about it? We, at that point, had a number of former and quasi-active Navajo alcoholics working for us at the center. I went up to meet Bob Hoover in Santa Fe, and I said, "Look, there's got to be something we can do about this. You've got these rehabilitation centers, they have a lot of money coming from the state from a special tax." I think it was a tax on liquor that was supposed to go for rehabilitation. I said, "Why don't you have Indian people going through your rehabilitation centers?" He said, "Herb, it's a language thing. We've had a couple of Indian people come, they don't seem to understand the language." I said, Look, that's no excuse. I will get you a group of Navajo men and women who are bilingual. If I do that will you accept them?" He said, "Fine." He was very positive.

I got him two men, Henry Tsosie and Wilson Begay. They went to Turquoise Lodge. I think the stay there was two or three weeks. The program was a good one. Then they came out, and when they came out we got them jobs at the center. Then we got other people: Henry and Begay started kind of acting like counselors to Navajo alcoholics. We started to build up, and that was the point, I guess, of my first direct rehabilitation experience. I don't know that it went very far because the problem of Indian alcoholism is very pervasive and it's still a problem.

O'Hara: It probably has deeper roots than [inaudible].

Leibowitz: But the important thing was that it was a lesson to me that things could be done, and that there were resources that you might use differently and creatively to reach people and bring about some change in some cases.

O'Hara: And how long were you there?

Leibowitz: I was there for two years and then I spent one year in Santa Fe with the New Mexico Public Health Department as a community mental health consultant.

National Federation of Settlements, 1959: Personnel
Director

Leibowitz: Then we went back East again to New York where I spent a brief time with the National Association for Mental Health, and then spent almost four years with the National Federation of Settlements.

O'Hara: What is that?

Leibowitz: That's an old agency that was involved in coordinating over three hundred settlement houses and neighborhood centers around the country. Are you familiar with the settlement house movement?

O'Hara: I think [inaudible].

Leibowitz: Hull House in Chicago and--

O'Hara: Yes. For the future historian, would you give us a definition? What's a settlement house?

Leibowitz: The settlement house movement started in the 1870s in London with the first settlement known as Toynbee Hall. Then it started a few years later in the United States, in New York. Essentially it was an approach to serving communities and neighborhoods by university students. The first settlement houses were set up by university students who went to live in the neighborhood.

O'Hara: So the house was used for housing university students.

Leibowitz: No. That might be part of it, but it became more of an activity center where, as they used to say, the neighborhood was the client. For instance, in New York the Henry Street Settlement was one of the first. At Henry Street, a Lillian Wald was the first director. When she got there and started services in this community which was mainly immigrants--at that point Jewish; it had been Irish before--and the tremendous need was for health services. So they started at the Henry Street Settlement what became known as the Visiting Nurse Association. It was an attempt to relate the immediate problems of the neighborhood, of the people in the neighborhood, to the development of new and creative services.

O'Hara: What was your role?

Leibowitz: I was the personnel director for the National Federation of Settlements and Neighborhood Centers.

O'Hara: And what did you do?

Leibowitz: Well, I had to recruit people into the field of settlement work. I helped to develop recruitment activities. One of the things I developed in Chicago was the Hull House weekend. We wanted to get young people interested in settlement work, so I got the people at Hull House to agree to host a group of students I hoped that we could recruit from around the country to come to Hull House. I think it was like two or three days. It was an experiment. I remember we sent flyers to every sociology department in the country, announcing the Hull House weekend. There was no charge for it; all they had to do was get there.

O'Hara: Did it work?

Leibowitz: It did.

O'Hara: You did more than one?

Leibowitz: We did two, I think. And it was amazing because people kept saying, "Are these kids going to know about Hull House? Is it going to mean--" and yes, they did. Hull House, Jane Addams was the director there. At the point where we did this--

O'Hara: Was she still around at that point?

Leibowitz: No, no, she was dead--but not too far gone. It was a great success. It was a beautiful thing.

O'Hara: What happened to the settlement houses?

Leibowitz: The settlement houses got caught in the whole black power and race relations revolution. The settlements were never heavy on services to black communities. There still are some settlements going, but not hardly what they used to be. But I was there for four years, and then I was offered a job here at Berkeley in 1963.

O'Hara: How did they find you?

Leibowitz: Well, it was interesting. I had gotten my doctorate at Teachers College at Columbia.

O'Hara: In teaching?

Leibowitz: No, in guidance and student personnel administration.

Social Welfare Extension at UC Berkeley, 1963-1969:
Director

Leibowitz: After I finished my degree I still had contacts with many of the faculty people because I had essentially been a faculty person while I was working on my degree. One day Paul Essert, who was head of the adult education division, and with whom I had some conversations about settlement houses--I was trying to develop some new sort of program at Teachers College--he called me and said, "Herb, listen. If you're interested in going back to California I just got a call from Paul Sheets," who was the director of continuing education at UC [University of California], "and he's looking for somebody to direct their social welfare extension program." So I said, "Great!" I called Paul Sheets, we had an interview. I came out for an interview here at the School of Social Welfare and Continuing Education. I got the job and we moved out. I guess it was June of 1963.

O'Hara: Interesting time. What is comparable to continuing education now?

Leibowitz: It's still here. It's the extension division.

##

O'Hara: You arrived in Berkeley in 1963.

- Leibowitz: I was head of Social Welfare Extension, which was the only program at that point that the University of California had up here at Berkeley.
- O'Hara: They didn't have a department of social welfare?
- Leibowitz: Yes. They had the graduate school of social work, but in continuing education there was just the program up here that was sponsored by the graduate school and the extension people.
- O'Hara: What was Berkeley like in 1963?
- Leibowitz: It was a much more academic type of place [chuckles]. I mean, even physically the campus was so much more open. There were more trees, there was more green, there was more parking space even though it was not ever enough. I was there from '63 to '69 and a lot of tremendous things started to happen.
- O'Hara: Did those things impact on your life, your work? You must surely have observed the turmoil.
- Leibowitz: Oh, yes. That was a period--I guess it was '66 to '67--when the beginning of the Free Speech Movement--I walked across the campus when they dropped the tear gas. I was part of a march that went down Telegraph Avenue when the whole street was lined with National Guard people.
- O'Hara: You were marching?
- Leibowitz: Yes.
- O'Hara: So you participated in some of the--
- Leibowitz: Yes.
- O'Hara: What was the march about?
- Leibowitz: Then-Governor [Ronald W.] Reagan was trying to limit the activities around People's Park. The whole ferment was starting. There were crazy things going on on every side. It was a very, very sad period. I can still remember sometimes just observing. Berkeley became an armed camp. The National Guard was here. It was really like living in a military, closed community [May, 1969--Ed.].
- O'Hara: What did you think about all that?
- Leibowitz: It was fearful. I can remember feeling this tremendous anxiety, this tremendous sadness. And then of course a lot of

things started happening to the university budget. In 1969 I essentially lost my job because Reagan essentially manipulated the university budget to the point where continuing education stopped getting the kind of support it was getting through the state budget.

O'Hara: So there was a real funding problem in the late sixties?

Leibowitz: Yes. I stayed on for an extra year.

Peace Corps in Bombay, India, 1969-1971: Regional Director

Leibowitz: I was teaching at the School of Education, and then I was offered a job with the Peace Corps in India. Mick and I had wanted to do this for a long time, so from '69 to '71 we were in Bombay, India. I was regional director for the Peace Corps.

**Rehabilitation Services Administration [RSA], 1971-1990:
Research and Training Specialist**

Leibowitz: I should mention before I leave my work at the university that while I was here from '63 to '69 I had contact with Phil Shaefer, who was the regional commissioner for Rehab Services Administration in San Francisco. Phil and I got to be good friends. Also Lucy Ellison, who was one of his key lieutenants in the welfare division. I mention that because when I was finishing my tenure in Bombay, I wrote to Phil Shaefer and said, "Hey, I'm coming back. I'd like to remain in the Bay Area." He wrote and said, "Well, we're going to have a job as a research and training specialist opening up." Three or four months after we got back he called and said the job is open. I applied for it and I got it. That was, again, the beginning of a very exciting period. The job I got was a brand new job that had been set up in 1971. They hired ten research and training specialists in each of the ten regions--one in each region. It was a brand new job.

O'Hara: You made of it what you wanted, or what you could.

Leibowitz: Right. What it meant was that I was responsible for working with the rehabilitation community, the disabled community, or the community of people with disabilities, and the universities

around the whole question of what sort of research and training programs might be developed. Again, it was a tremendously creative kind of job.

O'Hara: You were working for Rehab Services Administration?

Leibowitz: Yes, which at that point it was still part of HEW [Department of Health, Education and Welfare].

O'Hara: And they were interested in linking with university research?

Leibowitz: Yes.

O'Hara: And people with disabilities?

Leibowitz: Yes.

O'Hara: [inaudible; crosstalk]

Leibowitz: No, no, you see, it came out of the Rehab Services Administration [RSA] in Washington. There had always been a research office with Jim Garrett and a lot of good people. But it had always been centralized in Washington. It was projected out to the states and the regions.

O'Hara: Was this projection part of the political times? To get directly to the people?

Leibowitz: Yes. I think that this was part of a tremendous change that took place during that ten-year period.

O'Hara: And what was that change?

Leibowitz: Well, part of it was the fact that there was the civil rights movement, there was activity in communities where people were expressing themselves, where people were demanding answers, and it was starting to happen, I think, within the community of the disabled. You have to remember also that at that period, I think, the first large group of college graduates with disabilities started to move out--Berkeley being a prime example.

O'Hara: Did you ever see any of those students in the sixties when you were teaching there? Did any of them ever come to your attention?

Leibowitz: No.

O'Hara: It was a very small group. But Ed [Roberts] was there from '62 on.

Leibowitz: Yes. But I never knew them while I was there. But then starting in '70, '71, it was a group. The disabled students' group started.

The First Call from Disabled Students at UC Berkeley,
1971

O'Hara: Was your job with RSA your first contact with this group or your first sort of awareness with the group?

Leibowitz: Yes. At one point or another I got a phone call, and I don't know whether it was John Hessler or there was another young man in the group. He kind of had an Italian name. I remember John Hessler, I remember Herb Willsmore--

O'Hara: Larry Langdon was there. Not Larry?

Leibowitz: Maybe it was. Was he a kind of a short--

O'Hara: He was a thin, blond quad.

Leibowitz: No, he wasn't blond; he was dark-haired. And there was one young woman.

But at any rate I got a phone call; it could have been either Herb or John Hessler. It was before Ed was involved at CIL [Center for Independent Living]; I think Ed was teaching or something at that point. I got this phone call, and a group of disabled students was interested in finding out what opportunities there might be available in research and training. You have to remember that, at that point, in 1971, Rehab Services was a very traditional agency. It had been in existence for about fifty-five years. It had a very defined frame of reference. It was set up to help disabled individuals get back to work.

The process was very cut and dried. In each of the fifty states there was the same process: it went by the numbers. You went to the rehab office, you filled out an application, and the first step was being certified as being disabled. Now you could either pass that test, and if you were certified as disabled you were in. Rehab could buy you almost anything, could send you to college to get a Ph.D. if that's what you

needed to get back to work. But if you didn't pass that step you were out. We can't serve you because you can't be certified as being disabled. Many of the disabled students were affected by this along the way because they wouldn't have gotten support through Rehab to go to college.

O'Hara: Why not, if that was a Rehab mandate? They weren't certified?

Leibowitz: Right. For one reason or another. For instance, Ed was told when he came to California Rehab, "You're too disabled. We can't help you." Too disabled? But you see, that was the dilemma. The Rehab counselor was in a sense Solomon and made the decision.

O'Hara: Disabled but able to work in the counselor's opinion. That was the criterion.

Leibowitz: That was the criterion. Is it realistic? And Ed was too disabled? "You're going to go to college?" See, what started to happen in the early seventies was that this growing group of young men and women--Herb Willsmore, John Hessler, Ed Roberts, Judy Heumann--were you in Chicago still at that point?

O'Hara: I was here in '72.

Leibowitz: Did you come as a student or to work?

O'Hara: Just for a summer. I was teaching high school out here for three years.

Leibowitz: At any rate, when I came into the job at Rehab Services--'71, going into '72 and '73--when I responded to the phone call and I came over to visit--I think it was on Durant Avenue that they were borrowing an office, and they borrowed furniture--

O'Hara: Is this the one behind Top Dog?

Leibowitz: Yes.

O'Hara: Oh, that was their office.

Leibowitz: Yes. I remember coming in and sitting down. They were a very effective, smart group. We started to talk about what might be available, and I immediately felt that this is the new kind of rehabilitation.

The Independent Living Concept and Rehabilitation
Services Administration

- O'Hara: Now, how did you get to that conclusion?
- Leibowitz: Well, [chuckles] part of it was just feeling.
- O'Hara: You weren't a dyed-in-the-wool rehab person.
- Leibowitz: No, I was never accepted by the rehab people. I came from a social work background. My approach to people was completely different from the traditional rehab doing-it-by-the-numbers. So I went back to the office. For one thing, I immediately started talking to John and Herb Willsmore and the group there about the possibility of a training grant.
- O'Hara: That's what they were after? Training?
- Leibowitz: No, they didn't know what they after [chuckles]. They were wanting to find out what sort of resources--
- O'Hara: For what? Did they have any idea? Were they thinking of CIL at that time?
- Leibowitz: I think there may have been some idea, yes. Did they call it CIL at that point? I don't know. I can't quite remember. I went back to the office in San Francisco and I went in to see Dale Williamson who was the commissioner here. Very lovely guy. I said, "Dale, I think this is a new kind of rehabilitation." And then immediately there were people in the office who said, "That's not rehabilitation."
- O'Hara: What did they think?
- Leibowitz: There was only one kind of rehabilitation, Susan, and that was by-the-numbers. It was like a military setup: this is what the law says, this is the way you do it, don't tell me about anything else.
- O'Hara: How was John and company's approach not by the numbers? What did you see as the difference?
- Leibowitz: You mean John Hessler?
- O'Hara: Yes.
- Leibowitz: Oh, because they were talking about what to me was a new kind of participation, for one thing, by disabled people. They were

just proving by their own activities that there's a community base here, there's all the stuff that went on at Cowell [Hospital] that got us here, and that was just about the point where they got the curb cut stuff through the city. It almost reminded me of the settlement house approach: here was a completely new community starting to say, "Hey, we can do this and that, and we can run our own lives." That was where this whole concept of independent living came out. And the question soon became, "Is this stuff known as independent living part of this rehab process or is it something completely different that ought to be in another department?"

O'Hara: Has that ever been answered? [laughs]

Leibowitz: No, but it's been argued. You have to remember that, at that point, independent living was a completely new concept. It wasn't on the books. So at any rate, Dale Williamson was very accepting. We were lucky at that point. We had a certain amount of discretionary money in the regional office that could be used to respond to particular questions, situations, and demonstrations. I think the first grant that we put through was about \$50,000--was really very open-ended--I think it was part of some short-term training money. About that time Ed came in. They rented the space on University Avenue.

O'Hara: So this was the beginnings of the move away from PDSP [Physically Disabled Students' Program].

Leibowitz: Yes.

O'Hara: And so that \$50,000 went for that?

Leibowitz: Yes. For part of that--I mean, I never knew what the actual accounting was--but I know that part of that money helped set it up. I remember very dramatically one training program with Hale Zukas and Edna Brean, and I think Peter Leech may have been involved in it at the Berkeley police department. I sat in on the first session, and it was a revelation to have this room full of Berkeley police--and I think there were some firemen there also--sitting there listening to Hale making a presentation and being understood. Edna and some other people helped with interpretation.

And then when Ed came on, Ed and I just struck it off almost immediately.

O'Hara: Do you remember your first meeting with him?

Leibowitz: Yes.

O'Hara: Where was that?

Leibowitz: That was over on University. Ed and Joan Leon had just been hired to do development.

O'Hara: What was Ed like?

Leibowitz: He was bursting with energy. Bursting with energy. Full of ideas. The minute we met we were friends and colleagues, and it continued on over the years. It was a tremendous kind of relationship and very fortunate as far as I'm concerned, because I was convinced early on that this was the new wave of rehabilitation or activity for disabled people in the community. I assumed a role of kind of interlocutor between the traditional rehabilitation program and this new development that suddenly started to explode not just here but in New York and Chicago and in Boston. The Rehabilitation Services Administration just didn't know what was happening. We were lucky--

O'Hara: What were you hearing on your side? What were you going through on that side of it?

Leibowitz: Here in California we had this tremendously bright group of young people: Ed, John--you know the names of folks here in Berkeley. Then there was the group in Los Angeles. What's the name of the fellow who's now at UCLA? He was over in Inglewood and started the CIL there. He's now got a big administrative job at UCLA. You know him.

O'Hara: Doug Martin.

Leibowitz: Doug Martin, yes. Suddenly people started to interact. It was like explosions of activity and linkages between the disabled independent living group, and I started to play the role of interlocutor with the Rehab Services Administration. For instance, during that first two-year period, a group called me from New York and said, "Ed Roberts or Judy Heumann mentioned your name. Could you come and help us?" So I called the regional commissioner in New York, Tony DeSimone, and I said, "I've been invited to counsel with these people," and he said, "Sure, come on." In fact, someplace I have a letter from him thanking me for coming. He then became my boss out here.

National Conference on Independent Living, Berkeley, 1975

Leibowitz: At any rate, the independent living movement began to ferment. There was activity, et cetera. I was sitting in a very, very interesting position here, because for one thing we had Ed, we had John, we had this tremendously vocal group, and then Judy came out a little later. These were people who really knew how to express themselves! Then the coalition of disabled groups started all around the country, so that I started to get inquiries from people in Washington and in RSA. Everybody wanted to meet Ed Roberts. Of course, when he became the state director--wow. That was a completely new world.

One of the first things that we suggested as these things started to happen all around the country was, "Let's have a national conference. Let's try to get people together from the independent living centers but also from the rehab agencies." What we needed to develop was a coalition between the new and the old. You have to remember, at that point, that there was nothing in the Rehab Act that mentioned independent living. You had the '73 amendments coming up, and something was put in at that point, but there was no money. If you know the legislative, political process, it doesn't happen overnight. So what we did was get a chunk of money to have this national conference.

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O'Hara: You were about to talk about the conference. This is 1975, right?

Leibowitz: Right. The conference was '75, but we probably started the planning of it late in '73 or got a grant during '74. I think this was a short-term training grant that we got through Social and Rehabilitation Services. Let me just read this because I think it's appropriate. This is the beginning paragraph on this cover we put together for the minutes of the meeting: "It seems particularly appropriate in this bicentennial year to present this collection of papers based on the inalienable rights of severely handicapped able to enjoy the benefits of alternative and expanded opportunities for rehabilitation and independent living."

O'Hara: Who wrote that?

Leibowitz: I did.

O'Hara: Kind of a bold statement for your department, isn't it?

Leibowitz: Yes, well, you see the heading says, "An Old but Revolutionary Concept." The thing that I felt we just had to make very clear was that this was a new kind of input for rehabilitation. The questions that were being raised at that point were, "What kind of money will this program need? Where will this money come from? Will it steal from the existing rehabilitation budget?" That's one thing that your state directors of rehabilitation would not listen to.

O'Hara: They didn't want to reallocate.

Leibowitz: They weren't going to lose any money. They were going to Congress each year and saying, "Look. There are so many more people we want to rehabilitate," which meant by the numbers. The old rehab process.

O'Hara: When you wrote that statement--"An Old but Revolutionary Concept"--were you being very conscious there of the politics in the rehab community? Were you trying to draw them in by saying it was a revolutionary concept?

Leibowitz: Right. That was the point to it. Old-time rehabilitation people were smart enough to know that this was the next step. For instance, one of the people who was at this meeting at the Claremont was Miriam Stubbs. We had particularly invited Miriam because she was, as far as I'm concerned, without question, the smartest and best experienced person.

O'Hara: What was her role?

Leibowitz: She was one of the top administrative aides to Mary Switzer. Miriam had been a right-hand person to Mary Switzer for many years.

O'Hara: And Mary Switzer had been a director of RSA?

Leibowitz: Oh, sure. Mary Switzer was the patron saint of RSA. We invited Miriam Stubbs to this meeting, and I remember she was agog. Here she was with a group that included Judy Heumann, Ed Roberts, some of the smartest people in the country. People came from all over to participate.

O'Hara: From all over the country to this conference?

Leibowitz: Yes. It wasn't a big conference. I don't think we had more than maybe fifty or sixty people.

O'Hara: Why was it significant?

- Leibowitz: Because it was the first time that, for one thing, we introduced this concept of independent living. We had a big drawing of this chart, and it became a major part of the discussion. What this does is here's the individual--
- O'Hara: In the center of the circle.
- Leibowitz: Yes. And this is the disabled individual. The primary area, the most immediate area, is the family. They're interacting almost immediately. Then you've got your state rehab agencies set up to provide, from the point of disability, intervention, habilitation, rehabilitation. Then out here you've got all the range of elements that the Center for Independent Living can tie together to bring this individual back to full participation in society.
- O'Hara: And these were not things that the Rehab Department did.
- Leibowitz: No. All Rehab did was get you a job, train you for a job, if you were certified as disabled.
- O'Hara: They did not consider the need for accessible housing or attendants or any of the things that would support a job.
- Leibowitz: No, that's right. It was just three days: October 21 to 23. Then we had a set of beautiful papers that had been written by people who came and read them. Unfortunately we hired an editor who--well, it didn't work out. Finally we decided to just make a very nice cover and put the papers in this.
- O'Hara: You were going to make a book.
- Leibowitz: Yes. Originally it would have been a great book. They probably have sets of the papers--
- O'Hara: I think the [Bancroft Library] archivist has a set. I think Joan has a set.
- Leibowitz: Right. Joan would have them. I had many sets, but I don't know what happened to them.
- One of the points I started to make on this, Susan, is that sitting here in the San Francisco regional office, it became a center for work around independent living.
- O'Hara: Your office?
- Leibowitz: Yes, because I and those of us here who were starting the work with CIL and the people involved started to get calls from all

around the country. And then Dale Williamson set up a meeting here of all the regional commissioners. This was probably after this meeting, maybe. Maybe it was late '75 or early '76. They all came out to San Francisco and we brought them over to CIL on Telegraph Avenue--at that point they had moved--to see CIL. Boy, these regional commissioners were punch drunk to see this happening. If you remember the early days of CIL on Telegraph Avenue, it was a whirlwind of activity.

O'Hara: They were impressed, the regional directors?

Leibowitz: Yes.

O'Hara: I was under the impression that people outside--you're talking about state directors.

Leibowitz: I should say some of them were. The state directors are another story.

O'Hara: Okay. We'll get to that later.

Leibowitz: I think most of the regional commissioners could see what was happening here. And you have to remember that Ed Roberts was the state director at that point or he was going to be.

O'Hara: He was by October '75.

Leibowitz: Yes. So it was a tremendous lesson.

RSA Grants to Center for Independent Living: Peer Counseling, Wheelchair Development

Leibowitz: Now, other things started to happen. We got the research grant for CIL to do that peer counseling project [ca. 1972--Ed.].

O'Hara: That was almost \$350,000, wasn't it?

Leibowitz: That's right. That was a big grant. Again, there were problems involved with it. Let's see, Barry Ryan was involved in that, Sue Stoddard, and the director--

O'Hara: Don Galloway?

Leibowitz: Don Galloway, yes. They did a lot of work. I don't know that there was ever a report put out on that.

O'Hara: Was the administration of that grant in any way typical of what I have come to think of as maybe the lack of management experience of disabled people in general?

Leibowitz: Right. And this was a real problem. Let me give you another example of something that happened close by in relation to this. I had worked very closely with Joe Traub, who was head of Rehab Engineering for RSA in Washington. Ed and a group of the other people were interested in the possibility of designing and building a new wheelchair. So we went to Joe Traub, who brought along Tony Staros, who was head of the Veterans Administration [VA] Rehab Engineering. They came out. We visited CIL and then took them up to meet Ed in Sacramento and took them over to Nevada and Arizona to meet the other state directors. They were gung-ho. The fact is, they gave a grant to CIL to build a new wheelchair [ca. 1975--Ed.]. Have you ever seen that wheelchair?

O'Hara: No.

Leibowitz: It was built. It's around someplace. Actually, I don't know how many hundreds of thousands of dollars--and I can't remember the name of the engineer. Joan will know because the guy was a friend of her husband's.

O'Hara: Gordon Stout?

Leibowitz: No, no. They built a prototype, and then the VA wanted to develop an evaluation center for wheelchairs and prosthetic devices. That could have been a multi-million dollar center. Again, the management just wasn't there. It just wasn't there.

O'Hara: And what do you think is the reason for that?

Leibowitz: I think the reason--you have to say it honestly--is that personality got involved and it overextended the question of competence. There were some people that thought that because they wanted to do it, they could do it. And that's not the way it goes. It was too bad. I don't know if you've ever seen this [displays document]: it's the development of a model rehab engineering delivery system in California.

O'Hara: I don't think I have.

Leibowitz: You should take a look through this, because this was another absolutely earthshaking meeting that we had in Pomona.

O'Hara: Who is "we"?

Leibowitz: "We" was Ed and the state of California, Joe Traub, and Tony Staros of the Veterans Administration, and Jim Reswick, who was then head of the Rancho Los Amigos. We had this meeting at Pomona that was really earthshattering. I mean, the greatest people in rehab engineering were there. You read this. They came out with a plan for a model system.

O'Hara: What do you mean by "rehab engineering"? Products or process?

Leibowitz: Both. This was to develop a model delivery system. One of the things disabled people are always saying is, "I need a new kind of wheelchair. I need a new kind of prosthetic. I need something to make life easier or better."

O'Hara: So it is a technological idea.

Leibowitz: Yes. But the delivery of it--see, rehab engineers say they've got enough stuff on their shelves for the next million years. The question is how do you deliver it to people?

I point this out because this was another tremendously dramatic input that never really flew past the plan. Jim Reswick later went to Washington and took Joe Traub's place and became a big administrator. He's an engineer. If they don't have this in the archives, they should.

O'Hara: I don't think they do.

Leibowitz: Let me give you another example. This is exciting to me because I was living with all these new inputs. I think it was early in maybe '75 or '76 when I spoke to Ed first and said, "Here's what I think is happening, Ed. CIL's are being born all over the country with different approaches in different cities and different states. We're moving towards federal funding." That was between the '73 and the '78 amendments, and '78 is when I think the first dollars came up for independent living. Ed had already provided some money for the California CIL's--remember the first fifteen. I said to Ed, "What we should do is have a research project to start collecting and writing the natural history of the independent living movement." Ed said, "Great idea."

The next time I went back to Washington I sat down with George Engstrom, who was head of what was known as the research utilization branch in RSA. I said, "George, listen to this idea." George looked at me and said, "Herb, great idea. Can you write up an RFP [Request for Proposal]?" I went outside to his office and wrote up a Request for Proposal. I think it was maybe \$300,000 a year for five years to collect information,

develop a natural history. George announced it, and unfortunately again, California didn't get it. I had hoped that California was going to do it, but that was the money that started Lex Frieden and his program in Texas. It was a big disappointment. But you know, look at what Lex has done. That was his first step.

So that was the way things started to develop. And then more and more there were inputs, and Ed became a major player in the rehab field. Then there was the director up in Massachusetts and Illinois and New Mexico--disabled guys who became state directors.

Reflections on Ed Roberts and Judy Heumann

O'Hara: What was Ed's standing among state directors in general?

Leibowitz: It was interesting. I think with one group of state directors he was a peer and a buddy and a leader. Then of course there were the ones who weren't interested in anything new or different. I did a lot of traveling with Ed and he was tremendously respected.

O'Hara: What kind of thing did you travel to?

Leibowitz: He would go to Washington many times, and I would be there. We would get involved in meetings together and stuff. It was very exciting and productive. To me it was one of the most creative periods of my life. Things were happening. I was able to participate in so many of these developments. I don't know what the situation is now. At this point the independent living movement is kind of an old movement.

O'Hara: With its old sets of problems. I'm not sure that it ever got over the management issue--are you?

Leibowitz: No. I think that that has been and probably always will be a central issue.

O'Hara: How would you compare that with other civil rights groups? Do they have the same leadership issues?

Leibowitz: I think you have the same, sure. Look at what's happened. How does a civil rights and action movement start? It starts around highly emotional issues, and the primary movement is towards action. But then when you get to the point where the

emotional issues are past, and you have to really develop and sustain a bureaucracy--because that's what happens--you get a lot of people, you get a lot of organizations, and you need management. You can no longer get along with somebody getting up and making an oratory statement, because you've gone beyond that point. You need somebody who knows how to manage money, who knows how to manage people and organization. That's why a lot of civil rights and other action power groups kind of get lost in the mud.

O'Hara: But you stuck with this.

Leibowitz: For as long as I could, yes.

O'Hara: How long were you with RSA?

Leibowitz: I was with RSA from '71 to 1990. That was about nineteen years.

O'Hara: Were you always the research and training director there?

Leibowitz: Yes. And then my title changed a little because of the bureaucracy: I became special assistant to the commissioner for a while. It was a good job. It was a very creative kind of job. I think we accomplished some things. I have no idea what the independent living structure is in RSA now because I've been away for about eight years.

O'Hara: What was your involvement with Ed when he was state director? Was it an informal involvement?

Leibowitz: No, it was more than informal. I was in the regional office. When Ed became state director, my position certainly could give the people in Washington entrée [to Ed]. Ed and I had the kind of relationship where he could call me, I could call him, any time of the day or night. He would talk to me, and if I needed to see him there wasn't any time when I had to wait. So I became an entrée point for Joe Traub and Tony Staros, for instance, on rehab engineering. How many people could call and get an appointment to see the director of the biggest agency in the country in rehab without going through a lot of--. So I had a certain position.

O'Hara: Were you technically Ed's boss?

Leibowitz: No. And the commissioner is not Ed's boss. I was in a somewhat influential position. As I indicated, getting research projects started, getting demonstrations--

O'Hara: Were you at all involved in the establishment of the fifteen original CILs in California?

Leibowitz: No. I knew about it, and Ed spoke to me about it and stuff.

O'Hara: Were you during this time hearing things in Rehab that were--was there continuous negative components?

Leibowitz: No. I think that as independent living became part of the act --you see--what happened was that Ed and Judy were very good politicians. They did some of the primary work on the Rehab Act amendments and the definition of independent living and the funding of independent living. They became a political force. They brought about change.

O'Hara: Was it not a surprise to you when Judy was appointed to her present position as an assistant deputy?

Leibowitz: No. That was inevitable. Ed was interviewed for that same job years before when--what was the name of the gal who was head of HEW? She's from out here in California. She was a judge. Ed went all the way up to an interview with her, and she admitted to him that she didn't think she could work with him.

O'Hara: Personality-wise?

Leibowitz: No, something about his disability turned her off. Ed was very disappointed.

O'Hara: I didn't know he had gone that far.

Leibowitz: Oh, yes. But no, I wasn't surprised about Judy. And it's going to be interesting to see where Judy goes from where she is now.

O'Hara: How did you see her role in CIL when she finished her master's degree and joined the staff?

Leibowitz: Judy is a politician. She did some political things very well, but she also has her shortcomings. She does some things very well.

O'Hara: What did you see in those days that she was doing well?

Leibowitz: Judy has a tremendous capacity to kind of catch on to ideas and define them but then drop them. From my experience I saw this happen many times.

O'Hara: At CIL.

Leibowitz: Yes. Again, I think it's part of your mention earlier on of the need for management skills. There's a difference between creative brilliance, and Judy is a brilliant, creative woman. But I don't think she's a manager.

O'Hara: What did you see as Ed's strengths? What did his presence bring?

Leibowitz: Ed had a personality that kind of brought people together. He had a tremendous ability--he was a great speaker. I've seen Ed talk to groups--hundreds, thousands of people--and have them cheering.

O'Hara: [chuckles] What was behind his ability to attract the media the way he did? That's a pretty well-known fact.

Leibowitz: He was a very good politician. Was Ed Irish? I don't know what his background is. He was the good old-fashioned--he couldn't slap backs, but psychologically he could capture--

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O'Hara: You were talking about the "60 Minutes" program.

Leibowitz: Yes. Well, you can see in that "60 Minutes" program how he captured the media people and what a beautiful job they did of presenting Ed and his role here and around the world. Ed was a very unselfish guy. I think that was one of the key things in his personality: he was always wanting to get people in, get them involved and share. He was a very good friend. As I've told you before, I've felt a very special kind of relationship with him.

O'Hara: I wanted to go back even further to when you said you met with John Hessler and Herb at the old PDSP. What kind of a person was John? He was the director at that time.

Leibowitz: John was a very bright guy. John, I think, had a basically insecure feeling about himself. Again, he had a great personality. I remember he was very self-effacing. I always liked John.

O'Hara: Was he a leader?

Leibowitz: I don't think I can really answer that. I know he wanted to be a leader, but I think he was always kind of a second man to Ed.

World Institute on Disability, 1990-1996: Research and Training Center, and AIDS Project

O'Hara: Jumping ahead a little bit, I know that you did some work with the World Institute on Disability [WID]. Can you describe that? Was that with the AIDS project first?

Leibowitz: No, it wasn't with the AIDS project first. It started with a grant in 1990 from NIDRR [National Institute on Disability Research and Rehabilitation]. It was a research and training center. What was the name of it?

O'Hara: The Public Policy and Independent Living [PPIL] Research and Training Center.

Leibowitz: That's it, the PPIL. That came through right after I had retired. Judy and Joan called me, and they recognized that this was the first big NIDRR research grant that they had had, and they needed some help. So Judy asked me if I would be willing to help, and I was delighted. It was good: Judy was really very effective in setting things up. Some things got sidetracked again by poor personnel management and hiring, but essentially some of the basic things were very well done. Then after I had been there for a while things were moving along. Finished the first three years, I guess, and then it had to be renewed. It was renewed. Then Judy left to go to Washington.

Then I got involved in the AIDS project. That again was a very interesting input. That was a wonderful project. Elissa Chandler was the program coordinator or director. Elissa was a nurse who had had extensive work in AIDS in San Francisco. She was very good, and it was a very good program until it kind of fell apart [chuckles]. Unfortunately I still regret that AIDS project.

O'Hara: Didn't that have something to do with Caesar Perrotti's death?

Leibowitz: Yes. I think Caesar had been ill for a while before he died. So that project kind of went off the track. It's very interesting. The fact is somebody ought to do a little study on the question of management and disability projects. I don't think it's any different than any other kind of projects, but I do think that some emotional factors get involved. I remember the many, many disabled young--both men and women--who would come into CIL and WID, and they would announce without any shyness that they were going to be the new Ed Roberts. I think that that's a factor. It happens throughout the world

where people have aspirations that go far beyond their level of achievement.

O'Hara: Do you think it's particularly strong in this community?

Leibowitz: No, I don't. I think if you did a study you'd find the same thing. It's just that this community is so much smaller. Just think of the projects that we've just spoken about in the last couple of hours that went off the track. As you yourself pointed out, I think it's a management challenge. And maybe it's a challenge that we still have to face and try to do something about.

O'Hara: And then there are those others that succeeded.

Leibowitz: Sure.

O'Hara: Looking back on your thirty years of work in the disability-related field, what kept you involved?

Leibowitz: Let me answer that from a kind of personal/selfish point of view first. I've always really wanted to think of myself as an artist, as doing creative things. I think in the work that I've done--from the Youth Project to the National Federation of Settlements to my job with WID and with RSA--I think that I've been involved in creative developments. I like to feel that I had something to do with that meeting and the report and that I had something to do with this meeting and some of the things that happened. That makes me feel good and makes me feel some sense of fulfillment.

O'Hara: You've been instrumental in some changes over these many years.

Leibowitz: Yes. That's what I think is important.

O'Hara: Anything else you would like to say before we leave?

Leibowitz: I'm still looking for a new job [laughter]. Actually, I've got to find some volunteer work to do and get involved.

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University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME I

Mary Lester

GRANT WRITER FOR THE EARLY CENTER FOR INDEPENDENT LIVING IN BERKELEY,
1974-1981

An Interview Conducted by
Susan O'Hara
in
1998



Mary Lester in doorway talking to Judy Heumann during the 504 Demonstration at the San Francisco federal building, April 1977.

Photo by Raddatz.



Mary Lester and Lynn Kidder at the wedding of Phil and Sharon Draper, April 8, 1978.

Photo by Betty Medsger.

TABLE OF CONTENTS--Mary Lester

INTERVIEW HISTORY	32
BIOGRAPHICAL INFORMATION	33
I CENTER FOR INDEPENDENT LIVING	34
From New Jersey to Berkeley	34
Receptionist at CIL, 1974: A Busy, Social, Informal Environment	35
Staff and Services	39
The Move to Telegraph Avenue	42
The Research and Development Project	44
Ed Roberts' Hiring Practices	46
Turning Point: Ed Roberts Leaves, 1975	47
Comparison of Ed Roberts and Phil Draper	51
Antioch West: Master's Degree Project	52
CIL as Magnet	56
Smooth Transition to New Leadership	58
Thoughts on Judy Heumann's Goals and Vision	60
II CIL: COMPLEXITIES OF GROWTH	64
Grant-writing and New Funding	64
Funds Management	67
Trouble with the IRS	69
Confrontation between Staff and Board, 1976	70
Board Tries to Oust Phil Draper	73
Board and Efforts to Unionize	73
Start of Computer Training Program	77
Separation of Computer Training Program from CIL	79
III INNER WORKINGS OF CIL	82
Personnel Policies, 1976	82
Complex Revenue Streams	84
Demographic Profile	85
Attempt to Start Oakland CIL with Black Panthers	91
Core Philosophy	92
Unspoken Problems	93
Excitement and Optimism	93
Founding of Independent Living Center in San Francisco	96
Reasons for Survival	97
Staff Names, 1974	101
Role of Nondisabled People	104
Lack of Training; Noncollaboration; Antiprofessional	105
Perception as Symbol	109
Phil Draper's Wedding	111
IV AFTER CIL	114
Disabled Children's Computer Group	114
Alliance for Technology Access	116

INTERVIEW HISTORY--Mary Lester

Mary Lester was invited to participate in the Disability Rights and Independent Living Movement oral history series because of her employment at the Center for Independent Living [CIL] in Berkeley in its formative years (1974 to 1981). She has an extraordinary memory for the people and events of the early days of the movement.

Mary began as a receptionist at CIL and then served many years as a grantwriter, two positions requiring extensive knowledge of the organization. As grantwriter, she frequently wrote explanations of CIL policy, actively involved with CIL personnel in hammering out definitions and positions. She was also much involved in the political and social activities of CIL.

Mary's interviews provide an insider view of the inner workings of CIL--the tumultuous growth, the leaders and management, the excitement and optimism, the occasional chaos, the tensions that arose as the fledgling organization expanded rapidly. She talks about the core philosophy, perhaps the one thing everyone agreed on. She is particularly knowledgeable about the complex revenue streams and concomitant financial problems.

The four interviews were recorded at the home of the interviewer, who has been acquainted with Mary since the 1970s. Mary reviewed the transcript and edited it lightly. She has donated a small collection of personal papers from her CIL days to the DPIM archive in the Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Susan O'Hara
Interviewer-Editor

March 17, 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

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BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Mary Louise Lester
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 Father's full name William P. Lester
 Occupation Editor Birthplace Seattle, WA
 Mother's full name Phyllis L. Lester
 Occupation Librarian/writer Birthplace Vancouver, BC
 Your spouse _____
 Occupation _____ Birthplace _____
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Where did you grow up? New Jersey
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Technology Access, dedicated to increasing access to
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 Areas of expertise grant writing; editing; nonprofit administration
including finance; the power of technology
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music; reading; textile arts

Organizations in which you are active Support Center for Nonprofit
Management; Independent Living Network

INTERVIEW WITH MARY LESTER

I CENTER FOR INDEPENDENT LIVING

[Interview 1: January 22, 1998] ##¹

From New Jersey to Berkeley

O'Hara: Mary, let's start with your background, where and when you were born, and where you went to school.

Lester: I was born in New York City in 1951, May 15, and I was raised primarily in New Jersey just across the river from Manhattan, sort of spitting distance of the George Washington Bridge. At the first opportunity, I left New Jersey--"fled" is another word you could use.

O'Hara: As an adult?

Lester: As an eighteen-year-old. I got as far as Northwestern University at that time. I had hoped to get as far as California but that was just not acceptable to my mother, who thought that Chicago was already way far enough away to begin with.

O'Hara: California in 1969 [chuckles].

Lester: Right.

O'Hara: So did you attend Northwestern?

Lester: I did. I attended Northwestern for a little over two years, at a time that was very extraordinary for Northwestern. My freshman year was the year that Kent State happened. I don't know if you were still in Chicago at that point or not, Susan, but the whole Midwest just erupted. And the university actually made a very concerted effort to bring in a more conservative student body in

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

the following years, and they were very successful. I packed up stakes and I actually came out to UC [University of California] Berkeley the summer of '71 to go to summer school. I transferred in January of '72 and rarely looked back.

O'Hara: So you continued at UC.

Lester: Yes, I graduated from UC in March of '73 with a B.A. in cultural anthropology.

Receptionist at CIL, 1974: A Busy, Social, Informal Environment

O'Hara: You must have approached CIL soon after that.

Lester: Fairly soon after that. When I initially got out of school I was terrified. And especially since I finished early because I went to summer school. So one day I was in and the next day I was out. You have 180 units, you're done, you're educated, and it's pretty scary. So I did temp work. I did a series of temporary jobs for about a year and a half. And then it was in the late summer of '74 that I happened back to the university. I was living at this point in San Francisco. I went back to check out their alumni employment resource services, and there was one counselor there who had organized the job announcements in terms of profit companies and nonprofit companies. I thought, "Oh, this makes a lot of sense. I'll just look in the nonprofit companies." There was a job announcement for the Center for Independent Living, and she said to me, "I have no idea what that is."

O'Hara: She didn't know what the organization was?

Lester: Right. No idea what it was. This was September of '74, so they were looking for receptionists. I called and set up an appointment to meet with Phil Draper and Carol Fewell.

O'Hara: What were their roles at this point? Did they have titles?

Lester: They did. Phil was the assistant director. Ed [Roberts] was the director at this time, but had not been the director for very long. If Phil wasn't the assistant director then he was the manager of client services. But I think he was the assistant director. There were twenty-five people on staff. Only three of them were full time. It was funny: when I went over, the guy who was functioning as receptionist thought that I was there to apply as an attendant to do attendant work. They hired me as the receptionist. During my interview I had told Phil about one of

the temporary jobs I had had working for a microfilming house--I used to sit in an attic on a very high stool among boxes of PG&E [Pacific Gas and Electric] bills and pull staples out of them; it was like something out of a Dickens novel moved to San Francisco in the late sixties. I was there with all these other people who had B.A.'s, and one guy had a master's in library science [laughs]. It was a trip.

O'Hara: And you told Phil this in the interview?

Lester: Yes. It was on my résumé that I had had this temporary job. He said later that anybody who could do something like that could do work here [chuckles].

O'Hara: Had you had any experience with people with disabilities before this? Or was this a brand-new experience for you?

Lester: No, it was brand new. In high school I had been a camp counselor for an organization whose campers had brain injuries. Kids with brain injuries. But I really didn't even connect that. It was just kind of a natural thing. I remember Janice Kronos, who was the dispatcher for the Volkswagen bus we were using for transportation, saying to me one day that I just seemed to belong and seemed to just be really comfortable in that environment.

O'Hara: Where was CIL at that time?

Lester: CIL was at 2054 University Avenue. Second and fourth floors--mostly second.

O'Hara: Tell me what it looked like as you approached up the stairs. What did you see?

Lester: There was this huge marble staircase that was very--the steps were all bowed from years and years of being worn down. It was a funky place. I remember the plaster coming out of the walls right about foot-pedal-level from all of the corners [laughter].

O'Hara: You mean about nine inches from the ground?

Lester: Yes [laughs].

O'Hara: What was that from?

Lester: There were more wheelchairs in one place than I had ever seen, not having spent much time in hospitals or anyplace else where people congregated. When I started my first day on the job, Carol Fewell was going to train me. Midway during the day Ed came in and said, "We're having a staff meeting." It turns out the staff meeting

was a going-away party for Carol. That was quite an experience as well.

O'Hara: Why?

Lester: People just didn't stand on a lot of ceremony, let me put it that way [laughs]. It was quite an experience. Everybody was there with their dogs and their party refreshments. People got pretty loaded.

O'Hara: There were a lot of dogs around CIL in those days, weren't there?

Lester: Yes.

O'Hara: Not guide dogs, just dogs.

Lester: There were a couple of guide dogs. There were two guide dogs typically, and then there were others. Ed always traveled with Tremor. One of the first things I remember having to do was clean up after Tremor. Tremor had a habit of throwing up in the middle of meetings.

O'Hara: Where was this party?

Lester: It was in the office. There was a large room. It's funny, I hadn't really tried to visualize the layout, but there was one room where everybody seemed to fit. I suddenly felt like I was at home. There was a lot of, as Gary Rowan (who was the wheelchair repair person) used to put it, "middle-class flotsam and jetsam" that had not known what to do next in their lives and wound up at the Center for Independent Living.

O'Hara: Was that a reflection of the early seventies, this middle-class flotsam and jetsam?

Lester: I think so.

O'Hara: Why?

Lester: For me, I went through school studying anthropology, and one of the focal points of my college career was the war in Vietnam, and a lot of things that people had taken for granted prior to those years people no longer took for granted. There was no clear-cut path; I've met people before--certainly a lot of people did have paths, but I certainly didn't have a lot of direction except sort of a general feeling about wanting to leave the world a better place than I found it. But I grew up in a family where education was a value in and of itself for the sake of education, and it was the primary value, which was not really so uncommon then.

O'Hara: Were most of the CIL employees fairly well educated?

Lester: Yes, I would say a lot of them were. I would say they had all graduated from high school and had completed varying numbers of years at college. I think probably a pretty good number of people did have degrees. There were also probably a fair number of dropouts. But they really did sort of represent the sort of late sixties and early seventies--trying to find a different way to go about living in life.

O'Hara: So this was your first day, the going-away party for Carol?

Lester: Yes. And then Carol was gone.

O'Hara: And she was your trainer.

Lester: Yes. So I sort of had to figure it out.

O'Hara: What did you do? What was your responsibility? You were hired as a receptionist.

Lester: I was hired as their receptionist.

O'Hara: What did that entail?

Lester: Answering the phones, making coffee. One of my primary responsibilities was unjamming the elevator. The elevator was very funky, and we had this giant screwdriver, and you had to wedge it between the doors to pry them open [laughter]. People were getting stuck in the elevator all the time. It would fit two power wheelchairs very snugly if they were standard-size power wheelchairs. There were a number of people that had larger size, and then that was just a one-person operation. The elevator was always getting stuck. In fact, not too long after I started working there we received an eviction notice from the fire department because, in the course of the months that I was there, we had to call them five or six times; we couldn't get the elevator going again, and they had to bring people down those marble stairs from the second floor and sometimes from the fourth floor. The fire department had just had it.

O'Hara: They would carry people in their wheelchairs?

Lester: Right. Some of those people, like Phil, he was probably 6'2" and weighed 200-plus. And with the wheelchair it got really bulky.

O'Hara: What did the fire department eventually do?

Lester: They sent us an eviction notice saying we had thirty days to vacate, but we could probably get ninety. This was actually probably a week after Joan Leon left for Europe, and I had been sort of temporarily put in as Ed's assistant. It was shortly after she left. So this would have been the summer of '75, getting on until May or June of '75. They said we could probably get ninety days. So Ed started scrambling to find a place for us to go. We didn't fight it the way we later fought the computer training project's being evicted from an upper-story building, because 2054 was unsafe and the elevator was consistently breaking down. We probably wouldn't have won. You needed a much more solid ground to stand on to fight that, which we later had and won.

In fact, what happened right after we got the eviction notice was Tom Fussy (wheelchair repair person) and I were on the roof one afternoon secretly having lunch, and this smoke started pouring out of the elevator shaft [laughs]. We immediately went downstairs and called the fire department and said, "Hey, you guys, there's smoke pouring out of the elevator shaft." Nobody was aware of it because it was all coming out the top. The motor had burned out. So the fire department, as I recall, that same day also had to carry a lot of people down the stairs. They basically said, "You can kiss any extension goodbye. You people are done in this building."

Staff and Services

O'Hara: Let's back up a little bit. Besides unsticking your elevator, what were your other jobs? Did you greet people as they came in?

Lester: Yes.

O'Hara: Were there a lot of people?

Lester: There were a lot of people. There were very many people.

O'Hara: Who was coming in?

Lester: Well, there were twenty-five people on staff. The second floor was the main place where we were providing service, so there were people coming in looking for attendants, although a lot of that happened on the phone. There were a lot of people coming in and visiting Ed. Starting around that time Ed was beginning to lobby in Sacramento with Jerry Brown [Governor Edmund G. Brown, Jr.] for his job as the head of the Department of Rehab.

O'Hara: How did he do that?

Lester: I'm not sure. He was networking, the classic networker and politician that he was.

O'Hara: He went for that job, then.

Lester: Yes, he did. It was my perspective that he was working very hard at getting that job. One of the ways he was doing it was to build CIL as a platform. They went after a couple of government grants at that time to sort of raise the profile. It was also a time when Neil Jacobson and Scott Luebking were beginning to put together the computer training project, so they had people from IBM coming in. It was a real growth spurt kind of a time.

O'Hara: What kind of services were available there? Was there wheelchair repair?

Lester: They were doing wheelchair repair on the fourth floor. Just as I arrived they moved up to the fourth floor because we were beginning to outgrow the space on the second floor. Blind services had an office--Don Galloway was the head of blind services.

O'Hara: And what did that consist of?

Lester: At the time it was pretty much limited to peer counseling, and Carol Wiebe was working out of CIL doing orientation and mobility training. She wasn't doing it in the office but she was in and out of the office because that's I think how it was getting scheduled. Attendant referral was going on; there were a couple of attendant referral counselors. Greg Sanders was doing advocacy counseling--SSI [Supplemental Security Income] and Department of Rehab type of stuff. Peer counseling hadn't really gotten going at that point; that really started later. Independent living skills really wasn't underway then. We did have a VW microbus driven by Norman, who was one of the three full-time employees. Janice Krones was his dispatcher.

O'Hara: Who did Norman drive?

Lester: Whoever called and asked for a ride. I never saw them, really. I know he used to drive Kitty [Cone] some. Kitty had some serious complaints [chuckles].

O'Hara: What kind of complaints?

Lester: Sexual harassment and stuff. So Norman actually wasn't there very long. He left shortly after I arrived [laughs].

- O'Hara: What were the twenty-five employees doing? You have wheelchair repair, Norman, and the transportation--
- Lester: Right. I could probably even make a list for you and go over them at some point but we had--
- O'Hara: Were they all doing services or were they developing ideas or--
- Lester: Joan Leon, for example, was working with Ed, beginning to do some development and grant writing. Nancy D'Angelo was really Ed's secretary, although she quickly shifted into doing attendant referral, I think, and Joan took on more and more responsibility for Ed's work and administrative stuff. Actually, I think at that point Phil Draper was managing all of the service end of things. So we had a couple people in attendant referral and a couple people in wheelchair repair, and Don Galloway in blind services, and Jan McEwen was writing The Independent, and Ken Okuno was taking photographs for it. Have you seen the early Independents, the newsletters, with those fabulous photographs? That was Ken. Then Lynn [Kidder] was doing Medi-Cal billing; she came on a month before I did.
- O'Hara: In '74 also.
- Lester: Yes.
- O'Hara: I see. Medi-Cal billing for the repairs in the wheelchair repair shop?
- Lester: Right.
- O'Hara: Now when a client came in you were the first person that person saw?
- Lester: Often, yes.
- O'Hara: What happened to that person? How did the person get into a process?
- Lester: Very often they had called first and sort of knew where they were going. But if they didn't, I would greet them at the door and ask them what they were interested in. We didn't have any sort of formal intake process at that point; that evolved much later on. A lot of the people who came in on a regular basis were friends and family; they came to hang out. It was a very social environment. A lot of people were just hanging out or they were coming for a specific meeting or they were coming for wheelchair repair, and they knew exactly where they were going. There wasn't really a need so much for appointments because it was a pretty

small operation and people felt pretty comfortable and free to just drop in. I think the majority of the attendant referral work was all done on the phone.

O'Hara: How did a client even get in? Were there automatic doors? How did they get in from the street?

Lester: I can picture it. There was a big glass door with metal bars across, about three or four feet up. And there were swinging doors, so if people were in chairs they would just push their way in.

O'Hara: How did they use the elevators?

Lester: I think the buttons were fairly low.

O'Hara: It wasn't the kind where you had to pull open the outer door?

Lester: No [chuckles].

O'Hara: You just had to unjam it!

Lester: I had to unjam it periodically, but it was theoretically fully automatic. Actually we were only in that facility, when I was there, until the weekend of July fourth in '75.

O'Hara: That was the moving date?

Lester: That was the moving date.

The Move to Telegraph Avenue

O'Hara: And that was moving to 2539 Telegraph?

Lester: Right.

O'Hara: Who found that place?

Lester: Ed found that place.

O'Hara: Do you know how?

Lester: It had been on the market for a very, very long time. He had been looking for a long time. There was an old nursing home facility that had been abandoned or vacated down on Sixth Street not too far from University Avenue, if I recall right. The old Berkeley

bowling alley, which is now the Berkeley Bowl--which is the big grocery store--was also vacant at the time and was sort of the other main possibility. There were all kinds of jokes about finding Ed down at the end of lane fifteen. But we needed something that was pretty centrally located and fairly easily accessible, but the big problem with Telegraph was it was so far from BART [Bay Area Rapid Transit]. That was unfortunate. But in terms of the space we needed it really was the best location.

O'Hara: And it was a rental at first?

Lester: Yes. We tried very hard to get Shel Ovale, the owner--it had been a British Motors car lot--to donate it.

O'Hara: You tried also? You were a part of that?

Lester: No, I wasn't part of that. Phil and Ed were part of that. I was certainly part of the moving crew, because we didn't hire any professionals [laughs], which I'm sure comes as no surprise. So basically it was the able-bodied people on staff who provided the muscle to move the organization the weekend of the fourth of July. I remember it well. Because also at this time we had gotten rid of the VW microbus, and I guess they just outright bought this International Harvester step van--like a UPS truck. And they painted it; it was great. There was sort of a contest about how this would be painted. It was Berkeley in the early seventies, and they had all sorts of grandiose [laughs] mural designs in mind. They wound up painting it bright orange. Screaming orange. It was called the Great Pumpkin.

O'Hara: What did they use it for?

Lester: This replaced the VW microbus, and they used it for transportation.

O'Hara: No windows?

Lester: No windows. But a lift.

O'Hara: Was it the only transportation available in town?

Lester: Yes, it was, besides BART. And AC Transit certainly wasn't accessible at that time. And BART started running in early '73, and they had just opened the BART tube under the bay in September '74. So the van was it, basically. Except the hospitals had their vans. A few clients were making trips to hospitals for appointments.

O'Hara: So did you use the Great Pumpkin to transport things for the move?

- Lester: Yes, as I recall we did. I think we got it right around that time.
- O'Hara: How did that work with the able-bodied people doing that kind of work? Was there a feeling that this was unfair? It was fun?
- Lester: It was a time when everybody that could do windows did windows, and everybody that couldn't do windows did something else. We took out our own trash--that was just sort of the nature of the organization at the time.
- O'Hara: How did the organization get along on University Avenue? What was the atmosphere in terms of spirit on University?
- Lester: Primarily it was really positive. Everybody had a sense that they were doing something very unique and very unusual. And I think people thought it was really important. I don't think they understood how significant it was really going to turn out to be.
- O'Hara: You don't?
- Lester: I don't think so. I think a number of people did, obviously; somebody had the vision. And a lot of people did see this as a very important model, but I don't think everybody saw it that way.

The Research and Development Project

- O'Hara: Were phone calls increasing? Were people latching on to this idea?
- Lester: Not really while we were still on University Avenue. I think it was just beginning. I think that really began to mushroom later on after we moved to Telegraph, and we became a lot more visible. We were more of a showcase. We made for a much better tour. A number of things had begun to happen in terms of funding. The point at which the R&D Project started. It was the Research and Demonstration Project, funded by HEW [U.S. Department of Health, Education and Welfare] to do a peer counseling program, document it and evaluate it. That brought on a whole new raft of people.
- O'Hara: That was a large grant.
- Lester: It was a large grant. I probably have the figures with me, but it was a large one.

##

O'Hara: You were talking about the R&D, the peer counseling project, and you said that it had gotten a fairly substantial grant. Where did that idea come up? Was peer counseling an important concept right from the beginning?

Lester: Yes. I think basically the whole organization was founded on the basic premise behind peer counseling, which was people with disabilities assisting other people with disabilities and knowing best what the needs would be. As I saw it, the organization really grew as a reaction to the standard rehab system of services--the medical model--and counselors and service providers prescribing instead of advising, or guiding, or facilitating. It really grew up as a reaction to the status quo; peer counseling was an idea at the heart of that, although until the federal grant came in everything was being done peer to peer--not so much counseling in the more traditional psychological sense. It also took in independent living skills and things like that. It also had a major focus on research and documentation. It was the first real effort to evaluate our work and its impact.

O'Hara: How did it work? Was the primary object to teach others independent living skills?

Lester: I'm not sure, Susan. I can tell you who worked it. Don Galloway was the director of the project. Sue Stoddard, who is now the director of InfoUse, who then was called Sue Pflueger, was the evaluator that was hired to evaluate the project, and they came up with all these instruments to record service and evaluate and document. I know John McLaughlin was one of the first peer counselors, not sure about the others.

O'Hara: Right from the beginning.

Lester: Yes.

O'Hara: What about Hal Kirshbaum? Was he involved in that in the beginning?

Lester: He was involved in that. Hal Kirshbaum was on that project. I think that's how he did come in the door, now that you mention it. Linda Perotti was the secretary for the project. The one I'm not sure about is Phil Chavez; I'm not sure if he was on it or not, but I know that John McLaughlin was. And I think Cathy Duggan Roberts was also involved in it.

O'Hara: Was she married to Ed at that time?

Lester: I don't think so. I can't remember what year they got married. I think it was after that. I think she didn't marry him until he was in Sacramento, if my memory serves.

Ed Roberts' Hiring Practices

O'Hara: Did you see the romance blossoming at CIL? [chuckles]

Lester: Yes, oh yes. I'll never forget the day Ed hired Cathy. Cathy was on staff as sort of a consulting OT [occupational therapist], and Jan McEwen at a staff meeting--when everybody's gathered around--says, "Who are you and what are you doing here?" One of the questions people always had was, What project are they working on? Where is the money coming for this?

O'Hara: You mean the individual staff people questioned the source of the money?

Lester: Yes.

O'Hara: Why would they do that?

Lester: They wanted a better picture of what was going on and more information. It was a time when people were just showing up to work, and other people weren't apprised in advance, and some people wanted more information.

O'Hara: You mean just coming in and sitting down and doing a job or what? [laughs] Could you say a little bit more about that? Any examples you can think of?

Lester: Cathy's actually a good example. Cathy was sort of brought in and presented as being on staff one day, and people were very curious about what the plan was in general, what the project was that she was going to work on and how it fit into the scheme.

Young: Was that basically Ed's decision or was there a small group of people that met to discuss these hiring decisions?

Lester: No, actually there wasn't. Ed did make a number of decisions like that, brought in people to do various things. Eric Dibner showed up around the same time.

O'Hara: If Ed liked somebody he hired that person? Or did he basically hire anybody who approached him?

Lester: I don't think he hired anybody who approached him, but he hired a fair number of people right in that time zone from mid-'74 to mid-'75. I think, in his mind, Ed had a plan for what was going on and how it would all fit together, but no one else seemed to. As we said before, it wasn't a time when organizations--especially organizations like that--had a lot of role models in terms of strategic planning and all of that kind of stuff. The Support Center was a brand new organization that was beginning to provide consulting services to nonprofit organizations, but there wasn't the standard practices and guidelines and such that organizations have to follow now. People did have basic thoughts about what was needed in terms of building an appropriate infrastructure and management structure to support this kind of growth, but actually doing it was one of CIL's main problems. The programs were added and added without the accompanying underpinning in terms of management and infrastructure. It took a real toll.

Young: Was it rare that Ed made these decisions on his own, like with the hiring of Cathy? Or was that a fairly typical phenomenon at CIL?

Lester: Nothing was real typical at CIL [laughter]. I'm not sure anything happened consistently enough that you would call it typical. But there were a number of people he did hire like that. We didn't have a personnel policy in place at that point. In fact, it was later on that a committee was put together to develop a personnel policy, and I was on that committee. One of the things that we did was put in place this fairly elaborate, very egalitarian (or so we thought) system to hire people. We did get to a certain point where we absolutely had to have policies and procedures where we had none. Staff and funders wanted more accountability.

O'Hara: Most of these people that you've mentioned stayed quite a while. Were they absorbed into the system eventually?

Lester: Yes. They were valuable, dedicated people.

Turning Point: Ed Roberts Leaves, 1975

O'Hara: Who was holding this together?

Lester: In terms of day-to-day operations, Phil Draper was the one that was kind of managing things in a way. Phil was there more often than Ed. Phil was the one that I think a lot of people went to for guidance on day-to-day stuff. Ed actually wasn't the director all that long. He became director, I believe, sometime in early '74. I'm not sure about that. He was there when I came on. He

left to go to Sacramento at the end of October '75, I believe, at which time Phil became the executive director and Judy [Heumann] became the deputy director. So they brought Judy back from the East Coast; she came back specifically to do that job. It was kind of a package deal; that was something that Ed had set up. In order for Phil to be the executive director the team had to include Judy as the deputy director.

O'Hara: What do you mean?

Lester: Maybe "had to" wasn't quite the right way to put that, but there was sort of a vision about the organization moving ahead as more than just a direct services organization, and in order to do that there needed to be some strong players on that level, and Judy was one of them. I think that was the vision Ed had, and obviously it was shared by others because that's the way it happened. It was a huge turning point for the organization, a very important one.

O'Hara: Why?

Lester: Because it did, I think, elevate us to that next level. The whole organization had been growing rapidly at that point, and with Ed's going to Sacramento, that was one of the things that raised the profile of the organization. Certainly in the state it raised the profile of the organization. Actually, right before Ed left he put on a dog and pony show for CSAVR--Council of State Administrators of Vocational Rehabilitation. So it was all the heads of all the state DRs [Departments of Rehabilitation].

O'Hara: Here in Berkeley he did that?

Lester: Yes. They did it up at the Claremont Hotel.

O'Hara: Oh, was that the Independent Living Conference?

Lester: No, actually it was right around that same time, but it was a separate event as I recall. The Independent Living Conference was the thing out of which CSAVR came, with all the papers that everybody wrote for it. I have some of those papers that were written for that.

O'Hara: The originals?

Lester: Yes.

O'Hara: Not the booklet.

Lester: The booklet.

O'Hara: Oh, you do have the originals.

Lester: Not the summary, but the papers--

O'Hara: Separate papers?

Lester: Yes, I have some of them. And Joan Leon did have them. With any luck--she threw them out years ago [laughs]. But anyway, it was the Independent Living Conference and the CSAVR meetings that really raised the profile of the organization too, and I think that was all part of Ed's networking plan.

O'Hara: What do you mean "dog and pony show" in this case? Were you there?

Lester: Yes.

O'Hara: And what was it? Do you recall?

Lester: In fact, I even bought new clothes for the event [laughter]. That's what I mean by dog and pony show, Susan.

O'Hara: Everybody had to look professional?

Lester: Yes, to the extent feasible. We were a motley crew all in all.

O'Hara: No suits and ties?

Lester: Some suits and ties. Not so many suits and ties. Ed wore a suit and tie.

O'Hara: To this event.

Lester: Yes. I'm sure he did. Phil didn't own a suit and tie. I don't know what Phil wore.

Basically we had a room and brought in a bunch of people to sit down with us. Bette [McMuldren] and I explained the history of the funding of the organization and how we built it in terms of all the dollars and how it evolved. There were a series of presentations made and there was a tour. That's what I mean by a dog and pony show.

O'Hara: A tour of CIL?

Lester: Yes. In many ways it was introducing still a very maverick concept to some people who really weren't that receptive to it.

O'Hara: How was it received that day?

Lester: I couldn't tell you. I was very anxious about it myself, because I was not in the habit of making public presentations, so I was kind of fixated and nervous. I think it probably went well. Joan would probably have a better perspective on that than I would. She was there, and I'm sure she was one of the orchestrators.

O'Hara: I wanted to go back to what caused us to talk about this question.

Lester: It was about Judy's coming to CIL.

O'Hara: Yes. You said she came back. She had been here doing graduate work and then went back to Washington?

Lester: I'm not quite sure about Judy's comings and goings so much, because when I arrived she wasn't here.

O'Hara: Was there a possibility of her being named director? Who chose Phil? How did that all happen?

Lester: That's an interesting question. I'm not sure. Phil was the assistant director at the time. Phil had a lot of popular support.

Young: What did people like about him?

Lester: Phil was very personable. Phil was very honest and straightforward, and he was somebody that you could talk to and somebody who had a lot of integrity. He was very down to earth but also had an incredible commitment and dedication to the organization and the idea behind it. Phil was one of the founders. Phil had broken his neck in a car accident right after high school. That was in 1958, I think, and he just kind of bounced around for the intervening years and really found a purpose and a direction in CIL. People just trusted him. I'm a big Phil fan. I was a very strong supporter and fan of Phil's.

Young: It's interesting, from an outsider's perspective on CIL. I think a lot of people when they think CIL, they think Ed Roberts. You mentioned that Ed Roberts was really only the executive director for a year. Phil Draper was executive director for the better part of ten years.

O'Hara: Six, I think. From '75 to '81.

Lester: Yes, I think that's right.

O'Hara: To '82, maybe.

Comparison of Ed Roberts and Phil Draper

- Young: How does Ed hold such a strong presence and an image, having been the executive director for such a short time?
- Lester: Because Ed was really a front man. Ed was somebody who could really sell people on a concept, an idea. He had a lot of very strong characteristics shared by politicians. He had a way of captivating an audience and making a point. He was more an idea man. Phil was more of a--I'm not saying this very well, but Phil was more of a "get things done" person. Ed was more of a dreamer. He would sort of create an idea or situation and then leave it to other people to work out the fine details [chuckles].
- O'Hara: What were each of their approaches to the media?
- Lester: I would say that Ed loved and sought out the media, and Phil dealt with the media because he had to, not because he ever chose to or wanted to.
- O'Hara: It's well known that the media was very attracted to Ed. Why?
- Lester: He was a charismatic guy. He was funny, he loved to tell this story about how he was refused as a client for DR because they said he was too disabled. And here he was the head of DR. They just loved that stuff. They would lap all that stuff up. When he was "on" he was really on, and he was good at it. I think he enjoyed it too, which is the major thing. Phil was much more of a private guy and more shy and also a lot less educated than Ed was. Ed had a Ph.D. from Berkeley, didn't he?
- O'Hara: He hadn't finished his dissertation.
- Lester: And I think that gave him a level of confidence. Phil had confidence in himself, but of a whole different nature. He was more grassroots, and had sort of come up a more difficult way than Ed had, even though they both had tremendous challenges. They were just really very different people.
- O'Hara: How about fundraising? Was Ed a good fundraiser?
- Lester: I guess he must have been. It's an interesting question. I always saw Joan as the fundraiser of that pair. But again, Ed was the front man and Joan was the writer and the negotiator.
- O'Hara: She actually said that she always went with Ed to meetings with fundraisers and that he would start out doing the talking and she would talk about the plan.

Lester: Exactly. Ed was never the sort of "how to get it done" kind of guy.

O'Hara: How about Phil?

Lester: Yes. He was. He was very nuts and bolts.

O'Hara: Did he talk to fundraisers?

Lester: Yes, and I used to go with Phil when he did that. He took on responsibility for fundraising when he became executive director when Ed left, November 1, 1975, I believe.

O'Hara: And how did that go, those meetings? What role did you each play?

Lester: I would say we kind of played equal roles. Probably not too unlike Ed's and Joan's, to tell you the truth. Although I might have taken slightly more of a back seat to Phil than Joan did to Ed. We would sit and talk about ideas and plans, and I would then do the writing and discuss the particulars with Phil.

Phil went on to do much more fundraising at CIL than I did. He got into the whole Friends of CIL and more of the individual donor kind of stuff. I did more of the grant stuff and liaison with government and foundation people.

O'Hara: Did he start the Friends?

Lester: Yes, he did. With Lynn and with Larry Herring [chuckles]. They set up the development office with Hal Kirshbaum and Lynn Kidder.

O'Hara: And when was that?

Lester: That was probably sometime in '76. And I think one of the first things they did was start the Friends of CIL, so it would have been Hal and Lynn. And then Hal moved out of development; it turned out not to be the thing that he wanted to do most. He and Dominic Harveston then set up the master's degree program through Antioch.

Antioch West: Master's Degree Project

O'Hara: Now that seems to me to be an extraordinary idea. Can you describe the beginning of the degree program at CIL?

Lester: You know who was involved with that was Pat Wright. I think that Pat Wright was connected with--I think it was called Antioch West. Is that right?

O'Hara: Yes.

Lester: There was another woman whose name I can't remember, and she and Pat I think approached Phil--Ed was gone--to do it. Maybe they first approached Hal Kirshbaum. I'm not sure. But Hal had a Ph.D., I believe, in counseling. Then they brought on Dominic Harveston. They set up this master's program. In fact, when Lynn and I were in Yucatán in--oh, here it is: in November 1975 we were debating whether we should go through it and get master's degrees in public health administration. I think that was one of the choices. That means it was getting going as Ed was leaving.

O'Hara: This was affiliated with a college called Antioch West, which was affiliated with Antioch College in Yellow Springs, Ohio?

Lester: I think so. That's my memory.

O'Hara: And where was this Antioch West?

Lester: It was in San Francisco, but they did all of those classes at CIL in the portables.

O'Hara: Did Antioch West have other classes? It wasn't just CIL.

Lester: It had other programs.

O'Hara: It was an accredited college?

Lester: Yes. They were beginning to get underway then at the end of '75. We were seriously considering going through the program. We chose not to because of the time and financial commitment, and the fact that it was totally untested. We were pleased with our decision down the road about that [chuckles].

O'Hara: Did people go through the program and get master's degrees?

Lester: Yes, I believe they did.

O'Hara: Were CIL people the instructors?

Lester: Hal and Dominic were two of the instructors.

O'Hara: Both of them had Ph.D.'s.

Lester: Yes.

O'Hara: What was Dominic's interest?

Lester: Dominic had a disability. His Ph.D. was probably in counseling or psychology or something. I'm reaching here big-time. He was one of those people that just appeared one day. Everybody just kind of appeared one day.

Actually, an interesting point is that I was the first outside hire that they ever did. I was the first off-the-street person that was ever hired at CIL. Everybody else knew everybody.

Young: It didn't sound like there were many advertised job positions. It seemed more that people became associated with CIL and were sort of absorbed. Then they found their role.

Lester: Right. When we started getting the serious government grants and stuff, we did the personnel policy, and then we started posting and doing announcements and bought advertising. Affirmative action was a very big thing in Berkeley at that time. It was particularly important that we maintain appropriate demographics in order to keep getting funding from the City of Berkeley and the County of Alameda. It was a big deal.

O'Hara: I'd like to come back to demographics; I think that's a whole other subject. But I would like to backtrack a little bit.

What was the actual facility like on Telegraph at that time? Was it just the one large building?

Lester: The car show room was the front, main piece of the building. There was a manager's office, and then there was the big huge open space in the back that had been used as the repair facility for the car dealership. So it was a concrete floor, cinder block walls. Then on the far end of the parking lot was an old series of garage bays. That's where we did van modification and wheelchair repair. Upstairs there was a little office where we did Medi-Cal billing.

O'Hara: Then later didn't CIL acquire or rent some space across the street for the KIDS [Keys to Introducing Disabilities in Schools] Project and DLRC [Disability Law Resource Center]?

Lester: Right. At first we rented on the north side of Blake Street. Blake is the one that comes in right in the middle of CIL. On the north side of Blake we had a storefront where we were doing job development. Then DLRC started working out of there but it was immediately too small. So we rented space in that place called the "old garage."

O'Hara: C.J.'s Garage?

Lester: Yes, where Fondue Fred is. They remodeled that. But actually that happened after we put the portables in the parking lot. So there were two portables that went into the main parking lot. That was probably about '77. One of them was at the far end that was used for counseling, and I think job development moved in there from across the street. In C.J.'s garage was DLRC and the KIDS Project. I think that was it. Then of course all this time the Computer Training Project was still across town. Because when that project started we rented space at 2020 Milvia Street.

O'Hara: Right away that's where they started?

Lester: That's where they started.

O'Hara: They were part of CIL at the beginning.

Lester: At that time, yes. For many years actually, they were part of CIL.

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O'Hara: You were saying that you were not around when the building numbers and sizes shrank. It was at its peak when you left in 1980, in terms of space.

Lester: And I know that when we bought the facility at Telegraph Avenue, maybe in '78 or something--I'm not remembering properly, but we did purchase it--I know that later they sold it and then I believe they bought it back. It went back and forth a couple of times.

O'Hara: Who engineered the purchase?

Lester: Phil was very instrumental in the purchase. They even set up an organization called Foundation for Independent Living, I believe as the holding company for the building, I think.

Young: That's right; I saw the incorporation papers for that, and I couldn't make sense of it. I never heard of that before.

Lester: Yes. I know that had to do with purchasing the building. I'm not quite sure how it all panned out.

Young: So there wasn't another center called the Foundation for Independent Living.

Lester: No. It was part of CIL.

CIL as Magnet

O'Hara: Once CIL moved to Telegraph was there an increase in the business, the clients? Were there other people coming? Was it busy around there?

Lester: It was extremely busy. There were all kinds of people dropping in. Again, a lot of it was social because it was a meeting place. It was a place for people to hang out and meet people and feel a part of the community. There was a real feeling of community.

O'Hara: How important was that?

Lester: Oh, it was critical. It gave people a sense of community, and it attracted a lot of people. CIL really became a magnet for people coming to Berkeley.

O'Hara: How did that happen?

Lester: I think a lot of it was word of mouth. Nancy D'Angelo and Judy-- and you'd be amazed how many people originated in Brooklyn and sort of all knew each other and basically spread the word. It was also, as you know, a pretty hospitable climate. It wasn't all CIL; a lot of it was the university and PDSP.

O'Hara: Was it more by word of mouth than media? Or was there any kind of concerted outreach on CIL's part?

Lester: To bring more people with disabilities into the city? No.

O'Hara: So they just showed up. It just grew.

Lester: It just grew. We would get letters all the time: what are the SSI benefits in California? What are the services? I remember a letter from Denise Sherer years and years and years ago that she wrote to Phil. I remember sitting down with Phil and answering it, because that was one of the things I used to do. I did a lot of Phil's writing. Phil used to hold a pen in his teeth. Basically he only signed his name and other official documents and stuff--phone numbers and whatever he needed to do. But by and large I did a lot of his writing. I remember giving Denise all this information about attendant care.

O'Hara: That's Denise [Sherer] Jacobson.

Lester: Yes. That was a hundred years ago [chuckles].

Young: Did you generally have this sense that there were more than you could handle? You said you didn't really worry about outreach.

Lester: We didn't worry about outreach a whole lot, actually. Or I certainly didn't; I felt that we were just trying to keep up and trying to do what we already said we were doing. We wanted to make sure we were doing it right and doing it well. In fact, it was one of the main points of conflict in the organization. I remember when deaf services was introduced. There was a lot of feeling that we were not doing well enough what we already said we were doing, and how were we going to expand to bring in another population? The subject came up again around people with mental retardation and developmental disabilities. How could we possibly expand and bring on new grants and new projects to serve this population when a lot of people didn't feel we were doing a good enough job on the other stuff we had already taken on? That's typical in organizations and especially one that really was trying to put together a coalition of disability groups. It was always a source of tension. CIL was continually being accused of being "quad dominated."

Young: Was the accusation accurate?

Lester: I don't think it was accurate, but I understand why it was said and where it was coming from.

O'Hara: Why don't we save that for the demographic section? It fits right in there.

I would like to go back to Ed again now, because he did leave in '75. What were his chief interests when he was there? How did he spend his time? You were his assistant for a while.

Lester: Yes, but just for a very short time. It probably wasn't more than two months. I was also doing a lot of other things, so when Ed was around I would be there to do whatever it was he needed done. It's interesting--it's not a period I remember really vividly. One of the primary things I did during that period was write that grant to the Department of Rehab--the I&E [Innovation & Expansion] grant--that got van modification funded and all those accessible vans. And the prototype wheelchair design project was a part of that.

O'Hara: When did you do that? You wrote those grant proposals?

Lester: Yes. Actually it was really interesting--it was one grant proposal, and it was the first one I did. It was written to the Department of Rehab to develop a new prototype wheelchair and to do a training program for people with disabilities to become

wheelchair mechanics. That was the major piece of that grant. Then the van modification part kind of got added later when it started to be implemented, as I recall. Also at the very last minute we were told that there was a lot more money, and Ed said, "Throw in vans and we'll do more transportation." So we did.

O'Hara: Was this your idea? Or did you conceptualize parts of it?

Lester: None of that was my idea. That had already been conceptualized by Ed and Joan, I guess.

O'Hara: But you wrote the grant.

Lester: Right. I wrote the grant with Gary Rowan.

Smooth Transition to New Leadership

O'Hara: Jonathan, you wanted to ask about Ed's leaving.

Young: You mentioned that there was a surge of growth in 1974 and 1975, and you also mentioned that Ed was seeking out this job at DR. Did anyone feel betrayed by him?

Lester: No, I think people felt really pleased for him. You mean because he left?

Young: Did that hurt CIL or did it help it because of the publicity?

Lester: Oh, I think it helped. For the most part it helped. I think one way we got hurt a little bit by it was we were no longer as attractive as a funding opportunity. Certainly the state wouldn't touch us because we were considered a conflict of interest suddenly. Department of Rehab funding ceased for the most part in those years because it was seen as a conflict, and nobody wanted to put Ed in that position. There was actually a lot of resistance to Ed's being the head of the Department of Rehab on the part of old-time rehab employees. They did not like the fact that this person was coming in from the outside. There was a lot of resistance to the fact that he was disabled. Any bureaucracy that's about to be shaken up is going to resist, and that's just the nature of the beast.

I heard through some sources that there were other people that were thinking of funding us who said, "Oh, well, they don't need us anymore because they've got Ed in Sacramento, and he can

provide everything they need. So they didn't fund us either. But we got through it; we got by.

I don't think anybody felt betrayed by Ed's going to Sacramento. I think everybody was really pleased and supportive of his success and what it meant, because it meant a whole lot more than just Ed getting a job in Sacramento; it was a huge turning point.

Young: Was it a pretty smooth transition for CIL having Phil Draper and Judy Heumann take the lead? Was the mission still essentially the same? Did people feel that the organization was still on track?

Lester: Absolutely. It's really interesting because I've been through a number of transitions to new leadership since then in organizations, and it's all been really difficult compared to CIL's transition. That was actually very smooth. I remember the party [laughs]. We had a lot of parties. We used to have these huge smash parties in that facility on Telegraph Avenue, and there was a huge--

O'Hara: With lemonade?

Lester: Hardly [laughter]. These people did like to party and get very loaded. And there was a big going-away party for Ed; a lot of people in suits.

O'Hara: You mean people from the outside?

Lester: Right [laughs]. Everybody understood the significance of that. It was a big deal. But the transition was very smooth. And I remember there was sort of this symbolic passing of the torch in a big huge staff meeting. It was the most natural transition I've ever witnessed. There was really no question about it.

Young: Was the torch passed to Phil Draper or was it sort of equal splitting, passing on to Phil and Judy?

Lester: It was passed to Phil because Phil was the executive director. Actually I'm not even sure that Judy was there right at that moment. In fact, I think it was a little while before Judy showed up, because she had some business she was finishing up on the East Coast if my memory serves. So yes, Phil was seen as the executive director and Judy was the deputy director.

O'Hara: How did that work out as director and deputy director--Phil and Judy? Did they have separate roles?

Lester: They did have pretty separate roles. They had separate interests and separate roles. I think they worked together pretty well. People learned how to play Mommy off against Daddy, to tell you the honest truth, in a lot of situations. If one of them said something that a person didn't want to hear, they'd go get another response from--[laughs].

Young: Can you think of an example of that?

Lester: No, I really can't. It's been too long.

Thoughts on Judy Heumann's Goals and Vision

O'Hara: What were Judy's main interests at the time that you were there?

Lester: She did a lot of traveling back to Washington and a lot of traveling around. She was more interested I think in replicating the model and creating a larger independent living movement. Phil, although he had that vision and was certainly supportive of it, dealt more with the day-to-day operations and fundraising and management and personnel and that kind of stuff. Judy was the one who brought in deaf services and was the one who always wanted to expand the population we were serving. She was pushing us in those directions to broaden the coalition. She was a networker supreme. I think they worked well together. A lot of people have a lot of different opinions on that, and I'm sure Phil and Judy would certainly have their own perspectives. I think, for the most part, it worked well.

Young: Was that interest in spawning new centers something that Judy primarily brought or was that something that was strongly there already and she carried out an existing role?

Lester: I think there was a lot of that already. I wasn't really involved in what happened there. There were some new people who came in and got to do the traveling and the model replicating, those kinds of things. I know there was some resentment on the part of people who had been there a long time that wanted to do more of that and didn't get a chance to. And that was also largely taking off around '79 or '80, so more of that happened after I was gone. I know that Judy and Bette were both very involved in making sure there was state funding for independent living centers. There was a state assembly bill that was passed to fund independent living centers in California.

O'Hara: Was that authored by Tom Bates?

Lester: Probably.

O'Hara: That's one of the people she worked closely with.

Lester: Yes, I believe so.

Young: Mary, you mentioned that Judy was very interested in coalition building. What function did that serve for her? What was she trying to accomplish?

Lester: Judy wanted to push CIL as far as it could go in terms of being a model and being a pioneer and bringing all of the different disability factions, if you will, together. Typically in the service world it was all very fragmented, still is. You've got your organizations who serve people with cerebral palsy and you've got your organizations who serve people with blindness. Then you've got your adult organizations and your kid organizations, and they don't typically come together. And those organizations very often don't collaborate. I think Judy understood the importance of building a coalition, especially to move a political agenda about independence and civil rights. You've got to have all of those ducks in a row and working together to make it happen, and she understood that better than anybody.

Young: How do you describe her success in pulling that together?

Lester: I think Judy's been tremendously successful. Certainly in later years she's clearly had an amazing impact on the whole community and the field. At CIL she was successful too. There were a lot of obstacles in the way, funding being the key one. Like I said, there was a problem that I felt very strongly about: the fact that the program aspect was growing faster than the infrastructure and the management to take care of that expansion. It was a real problem for us. But nobody wanted to fund administration; it's not sexy, it's not glamorous, and it's overhead, and the less you can get away with the better. So there are a lot of restrictions placed on nonprofits about that, and it creates real problems. Especially when you're growing at that rapid rate. There was a lot of government funding available. There was just a tremendous amount going on, and there wasn't nearly the competition there is now from other organizations for that kind of funding.

Young: To what extent were various staff members saying, "Hey, wait a minute. Let's not grow so fast; let's slow things down here. Let's keep things tighter before expanding"?

Lester: I think there were quite a few that were. I certainly saw myself on that side of things often--not always. I'm not sure.

Young: Was there a forum to discuss those things? Were there big meetings where everybody got together and talked about where to go?

Lester: We did have big staff meetings. They were more information sharing than they were open forums for discussion. Some of the more open forums for discussion were some of the board meetings [laughter]. Discussion is probably the polite term for a lot of what went on at those meetings. That's a whole other tape [laughter].

O'Hara: Were you at the board meetings?

Lester: Yes, I was at most of them for years. There are a couple that stand out in my mind, among others.

O'Hara: Back to Judy. She was perhaps one of the lead organizers for the '77 504 sit-in. She was at CIL then. Were you observing her at that time? Can you tell us about that?

Lester: I wasn't observing Judy so much. Judy was inside the building, I was outside the building. So my role in all of that was really keeping the office open, maintaining liaison, working with Phil. Phil was also outside the building, so we were basically outside the building just about every day marching and communicating and doing all of that other stuff and keeping the office going. And talking to reporters that called CIL. It's sort of a whole other set of things going on that really weren't in the limelight.

O'Hara: And the preliminaries for that were not discussed at CIL openly. Was that a very closed group?

Lester: It wasn't a closed group but it was a very busy group. As I recall it was Judy, Kitty [Cone], and Hale [Zukas]; you know, the people that were always doing the curb cuts and the architectural barriers--the bigger picture stuff.

O'Hara: Demonstrations.

Lester: Yes. Now early on, there was a whole series of demonstrations. In fact, one of my earliest memories was driving Don Galloway's van to Sacramento one rainy, rainy afternoon to fight the coming cuts in IHSS [In-Home Support Services]. They were going to cut attendant care money, which of course you know they do every single time it comes up. So those demonstrations went on year after year after year. In fact, there was a thing called the DBAC--the Disabled and Blind Action Committee of Northern California, which was a 501(c)(4) organization specifically organized for the purposes of doing more political work mostly

around attendant care money at that time--and those kind of issues.

O'Hara: CIL did a lot of lobbying and demonstrating didn't it? It seems to me that they rallied people a lot in those days.

Lester: DBAC rallied people a lot. We were always very careful about what we could be doing and what we couldn't be doing. But yes, we did a lot of networking and coalition building. We never had a paid lobbyist; we never did anything like that. But we did organize a fair number of demonstrations through DBAC.

O'Hara: I think we have come very near the end of this tape. Maybe we should call it a day.

II CIL: COMPLEXITIES OF GROWTH

[Interview 2: March 10, 1998] ##

Grant-writing and New Funding

O'Hara: Well, let's start with a little bit about the growth of CIL, how did it happen?

Lester: Well, when I started, which was September 24, 1974, there were twenty-five people on staff. And as we calculated, certainly by February of '76 there were eighty-eight. And I think there were a number of things that contributed to that rapid growth. One was the fact that Ed was director and was working on getting appointed by Jerry Brown in Sacramento and he was attracting a lot of attention. In particular, he was attracting a lot of government attention from both the Department of Rehab (state) and Rehab Services Administration (federal). He was a very charismatic figure and had a way of generating interest in, what at that point, was a very small operation. I think he was able to sell it in such a way that it just began to roll really quickly. It was also a time when there were new funding streams being opened specifically for community services. Revenue sharing--county revenue sharing--certainly became a funding source for CIL right around that time, right around the end of '74, the beginning of '75. I'm not sure when it was instituted but it made a tremendous difference because it secured basic services, attendant referral, advocacy counseling, and transportation.

O'Hara: What was revenue sharing?

Lester: Revenue sharing was actually--I believe it was a Republican concept and it was the county sharing its tax revenues with community-based organizations to provide services to the community. It was administered by the county and formed the core for CIL for quite a while. It was a brilliant idea. They had an application process that was voted on by the board of supervisors.

There was also city revenue sharing funds but they were smaller and it was also Berkeley and so there were, if you can believe it, even more politics involved than Alameda County. But according to the list of grants and contracts that Bette and I developed as the grants and contracts administrators, actually revenue sharing started in March of 1974 and it was for core services and administrative costs. And it was the backbone of CIL funding until Proposition 13 was passed. Then it was severely jeopardized.

O'Hara: Were funders seeking CIL out at all?

Lester: They began to. For a long time it seemed like we could kind of do no wrong. I remember one year when Martin Paley, who was the director of the San Francisco Foundation, came to us and met with Phil and me. Somebody had given some money to the San Francisco Foundation that was specifically earmarked for people who were blind or amputees and he asked us to write a proposal to provide services to those populations and we did. In a number of cases people from different facilities for the Department of Rehabilitation, and also RSA, approached us about projects. They would come to us and talk about the different sources, different pots of money they had and what they were looking for and as I recall, the whole process was much less difficult than it is now. The whole RFP [Request for Proposal] contract process that the federal government and states make you jump through now, is much less flexible. It seemed like everything we wrote pretty much was funded in those early years because we were very unique. And also, as I said earlier, the whole nonprofit world was much less sophisticated and more naive and flexible than now.

O'Hara: And were you doing the grant writing at this point? What are the years we're talking about?

Lester: I started grant writing in April of '75 when Joan went on the trip to Europe and there was a grant due for the Department of Rehabilitation.

O'Hara: And you never stopped?

Lester: And I never stopped. Once you start--

O'Hara: And what was the process for writing a grant? Did you confer with a lot of people or did you write a draft and then show it to people? Or where were the ideas conceived?

Lester: Well, that's a very interesting question and I'm trying to think about those early days. Very often what would happen is Ed would come and say, "We're going to go after this pot of money and this

is what we want to do with it. This is the plan." That was the case, certainly, with that first rehab grant--the I&E grant we already talked about. I went to a meeting where Department of Rehab facility specialist staff gave us the package of forms and went through the instructions line by line, and then provided an outline of what was needed for the narrative problem statement, and all that stuff. I remember that first one: Gary Rowan and I wrote it together. We were up all night sitting around his kitchen table in his apartment, which he shared with Neil Jacobson, and we wrote a grant to develop a prototype power wheelchair, train people with disabilities to be wheelchair repair people, and also to stock the wheelchair shop and really increase our capacity significantly. That was Ed's idea. And we just sort of put it down on paper and turned it in.

O'Hara: Did you have to flesh it out? I mean Ed was not--did Ed work on the details with you?

Lester: No, no.

O'Hara: You and Gary?

Lester: Yes, Gary and I worked on the details. But I do remember that after the grant was submitted, Ed came back and said that, "There is another hundred and X thousand dollars available through this type of grant and this pot of money. Let's add a bunch of vans to the project and that way get the transportation department launched." So we did. Very often it was a question of, "If you can write a grant and have it to us within a week, then you stand a pretty good chance of getting funded."

O'Hara: Was it always a frantic process of writing grants?

Lester: Always. It was always frantic. I never once--

O'Hara: Why?

Lester: Very often we would find out about these things at the eleventh hour. Very often it was the situation that I just described, somebody would say, "You know, there's this pot of money available, and the deadline for submissions is a week from now." It happened all the time. It still happens, I mean, [laugh] my life is no different in that regard. And I'm getting a little tired of it [laughter].

O'Hara: Is that how new units were formed, also?

Lester: Very often that's how new units were formed. Then when Ed left and it was no longer Ed that was germinating these ideas, it was

Phil. But also very often what would happen is somebody would come through the door with an idea and they'd say, "You know, I really want to do this project." And Phil or Ed would say, "Okay. Write the grant, try and get it funded, and then we'll take it on." I think in some cases the idea of incubating a project and then having it spin off as a separate nonprofit was part of the original plan, and sometimes the idea of spinning it off came up some time much later.

Funds Management

O'Hara: Was the administrative structure ever changed to accommodate all these reporting groups?

Lester: Not quickly enough. And in fact, one of the grants that Bette and I worked on was to the Rehab [Rehabilitation] Services Administration [RSA]. It was an establishment grant to computerize the financial accounting systems, record-keeping systems, and also to hire a grants and contracts administrator. And what we wound up doing, actually, was splitting that job. And it was through those funds that this report was generated. We also were able to put all the back records about grants and contracts in order and include them in the report.

O'Hara: And what is the name of this report that you're referring to?

Lester: This report is in three parts. The first is called "Center for Independent Living Grants and Contracts, 1972-1979;" part two is "Center for Independent Living, Inc., Foundation Grants and Contracts, 1972-1979;" part three is "Center for Independent Living, Inc., Corporate Contributions." It's a listing of the funding source, the budget, the period it covers and a very brief description of what it was for. Actually it was a facility improvement grant that funded us. That's what it was, and it started in '77.

O'Hara: And did that work out, then? Did it really help in the management?

Lester: Yes. It did help in the management. It was--well, it feels a little bit self-serving to say that, because one of the things it did was fund me and also Bette. Bette had been Judy's assistant up to that point and I had been Phil's and we then moved out of those positions and started focusing on working with the different departments in writing grants to government organizations as well as tracking them and setting up the tracking systems. So many of

the departments were multi-funded: there'd be a department that would have more than one grant or there'd be a grant that covered more than one department and it was really important to try and keep all of that straight.

O'Hara: Were you managing the funds, or just tracking them?

Lester: We weren't managing the funds. We wrote the budgets that were submitted with the proposals and we reported on those, on the expenditure of funds to the funding source, but we weren't authorizing expenditures. That was being done by Phil in conjunction with the comptroller. And the history of the accounting system at CIL was every bit--it just followed along with everything else. As we said earlier when the tape wasn't running, everybody was learning as they went along. Nobody had degrees in management, everybody had--if they had degrees, they were in political science, anthropology, and English and everybody was sort of learning as they went along. Nobody had any experience in running small businesses or nonprofit organizations; we just all had a passion for what we were doing and a commitment to doing it as best we could. And we had a lot of common sense among us and a lot of feelings about what we thought was right and applicable so that's sort of how we managed the organization. As I heard tell, Bill MacGregor volunteered to be CIL's first bookkeeper when people were just sitting around in the two-bedroom apartment on Haste Street (before CIL's move to University Avenue) trying to figure out their roles. Somebody had to do it. When we finally got a grant to hire a comptroller, our budget was in the neighborhood of \$800,000 I think. It was up there.

O'Hara: In those days that was a lot.

Lester: Yes, it was quite a bit. I think it was close to that, anyway. We were beyond the point that we should have been at that point really, but--

O'Hara: What do you mean?

Lester: Well, we should have hired more staff sooner than that. It got to be very complicated very quickly and so by the time we did hire a comptroller, things were fairly confused.

O'Hara: Why was it complicated?

Lester: Because of all the different funding sources and because of all of the reporting requirements.

O'Hara: How many funds at one time, approximately?

Lester: Well, just taking a look at the grants and contracts list, we've got--one, two, maybe ten funding sources--

O'Hara: In a year, or a project, or what?

Lester: Well, it's actually a little hard to tell by looking at this report because this is organized by the funding source; the first two pages are all Alameda County and then they go all the way from '74 to '79. I would say that we were dealing with probably six or seven different government agencies at any given point in time because we had City of Berkeley money, we had City of Oakland money, we had County of Alameda money, Department of Rehab, Rehab Services Administration, Agency on Aging, and then we had different titles within--for example, we had Title III and Title VI CETA [Comprehensive Employment and Training Administration] funding. Basically we applied to everybody for funds.

O'Hara: Now, when you said it got confused by the time you had a comptroller, what do you mean?

Lester: Well, by that point we were beginning to realize we were running a deficit. It was shortly after Ed left and Phil took over that we began to get a handle on exactly where we were and what the whole picture was in terms of our finances. We were running about a six thousand-dollar a month deficit--between six and seven thousand dollars a month, we were incurring.

O'Hara: In 1976?

Lester: In nineteen--yes, the end of '75, beginning of '76. Yes, it was probably about spring of '76 that we really began determining where we were.

O'Hara: Mostly the expense was staff costs?

Lester: Well, part of it was staff and part of it was the building because in July of '75, when we had to move at the insistence of the Berkeley Fire Department, our rent doubled, at least. And if my memory serves I think we were paying something like \$4,500 a month in rent. It was a significant increase for us. And the revenue to cover it hadn't turned up. So it was around that time in the spring of '76 that we realized what the situation really was.

Trouble with the IRS

O'Hara: Did the deficit catch up with the organization at some point?

Lester: Yes, it was around that time that it caught up with us. In fact, it had all sort of accumulated in one corner--which is, basically the rent got paid, and staff got paid, but it was the IRS that wasn't getting paid.

O'Hara: Payroll taxes?

Lester: Payroll taxes. And our debt to the IRS was about \$100,000.

O'Hara: In 1976?

Lester: I think it was '76. It might have been later in '76. And I remember having a staff meeting, sort of management staff, about how we were going to cover that and how we were going to borrow from our families or do whatever we needed to do to cover the IRS.

O'Hara: What did happen?

Lester: Well, one of the things that happened was we cut back on salary expenses and we cut back on other expenses. Then we worked out a payment schedule with the IRS. We had an agent that was assigned specifically to us. And in all of our naivete, we had decided that we would play ball with the IRS. We never had any intention not to play ball with the IRS, you know. We certainly wanted to cooperate, but we also had this notion that they wouldn't close us down, that the publicity would just be too horrific--throwing all these poor disabled people out on the street, you know, who needed that kind of PR? We felt invincible in some ways.

O'Hara: Was there some merit to that feeling?

Lester: Well, they certainly could have locked the door, and they didn't, so I think there was a certain amount of merit to it actually and the rest of it was just brazenness on our part, I think. Or again, a naivete about exactly how serious the situation was.

Confrontation between Staff and Board, 1976

O'Hara: Was there any staff tension over the management of the funds?

Lester: Well, there was more tension later on when salaries were paid late and then very late, and then even later. But at that point I think there was still a feeling of cohesiveness and cooperation. And one of the things that happened was--and I believe this would have been around July '76--the board of directors, in trying to cope with this situation, said that we had to lay off staff. They

drew up a list of who they thought should be laid off or cut back and it was our feeling that it was the role of the board of directors to advise the executive director that he needed to make certain cuts in expenses. That it was then up to him to make those choices about where the cuts would come, how they would come, who they would impact, and what services they would impact.

And so there was an infamous board meeting that occurred right around this time and it was specifically precipitated by this chain of events. Close to 90 percent of the staff was in attendance. This was at a point when there were probably somewhere between eighty and one hundred people on staff. The board was there and the board instructed Phil who to lay off--to abide by their plan. And Phil said, "No," that that wasn't what he thought needed to be done or the way it should be done. Then Lynn Kidder stood up and said, "Well, you know, Mary and I have talked this over and we feel that--we discussed what we would do if Phil did this and so we--I'm resigning." So we both resigned on the spot.

O'Hara: In opposition to Phil's decision?

Lester: In support of Phil's decision, in opposition to the instructions of the board. Within an hour most of the staff had resigned and we immediately regrouped in the wheelchair repair shop to figure out how we were going to keep the doors open, continue to provide services, keep wheelchair repair and attendant referral going. It was very much a staff versus the board event. There was that feeling and there was a real feeling of--I hesitate to use the word--solidarity, but that's what it was. So the next day the whole staff was assembled in the parking lot and the board was in the office and that went on for two days. Judy was on staff at this point, and she, of course, was with Phil and the rest of the staff. And the board had a real problem on its hands, to say the least. [laugh] Not to mention a PR nightmare that would keep anybody from sleeping for the next six months. I mean, the media was there; it was an event. And it lasted two days, and then the board basically backed down.

O'Hara: Who was on the board at this time? Who was the chair?

Lester: I think the chair was Peter Trier. I know he was on the board. I'm pretty sure Jack Rowan was on the board. I can't remember who else was on the board. I think the board--it was a membership organization so the board was elected by the community. You had to have two signatures of existing members to become a member of the organization. Once you were a member, you could vote on the board. I believe a third of the board could be made up of staff people. So there was, of course, the full one third on the board.

[laughter] And I actually remember at one point Ray Uzeta putting forth an idea to the board that non-disabled members not be allowed to vote for board members.

O'Hara: What was the feeling among the staff when the board backed down?

Lester: I think it was, "Okay, let's get back to work. We have a lot we have to do and we obviously showed the board that we care about the organization and we have more power than they do." I mean it wasn't a vindictive bitter thing, it was just, "Let's get back to it and get on with it." And it was sort of "the united against the common enemy" for a while.

O'Hara: Any long-term repercussions in terms of power of the board or staff cooperation with the board?

Lester: I don't think so. Well, actually, I think there might have been a number of resignations from the board and a lot of really hard feelings. I think that people on the board really did take a hit. Chuck Cole was on the board at that point, I'm pretty sure. He had been with the organization from the beginning. He generated a lot of anxiety within the board around the current issues. And I think they did feel besieged.

O'Hara: Was the board accustomed to calling these shots or was this an unusual circumstance?

Lester: This was a pretty unusual circumstance. Phil actually had been the president or the chair of the board up until the point at which he became executive director, so the connection between the board and the staff had always been very, very tight and very close. There wasn't a real separation of power there to speak of, I don't really think, which is also part of the common evolution of nonprofit organizations. So this was different. This was the first time the two groups ever went head to head. And it happened again later. In fact, I'm not sure how far down the road it was, but I do remember a time when the board tried to oust Phil. Yes, that was another one of those meetings that--you know, without valium and Maalox--[laughter]--it just wouldn't have been possible. I think that it was part of the residual resentment created by the work stoppage.

O'Hara: I wanted to ask you about that. Let me just turn the tape.

Board Tries to Oust Phil Draper ##

O'Hara: When was it that the board tried to oust Phil?

Lester: Well, I think it was probably in '77 or '78. I wish I could be more specific about that; I probably could as we talk and I tie it to other events. I don't even remember what precipitated it but I do remember there was a board meeting that happened up at the Theological Seminary behind CIL up there on Hillegass, I think it was. Debby Kaplan was at that time the president of the board. And Debby was a Phil-supporter, as I recall. But there was a faction that was trying to oust Phil and I really don't remember the details of it but I just remember it being an incredibly stressful time. And Phil prevailed. Phil had a lot of supporters and his share of detractors. But there was a lot of friction between the board and the staff, I think probably dating back to the work stoppage. I think you might be right that there was a tension that was established at that point.

O'Hara: The two-day stoppage that you talked about?

Lester: Yes. I haven't really thought about it, and of course, now with the time frames being so much fuzzier it's kind of hard to know.

Board and Efforts to Unionize

Lester: I have a number of memories about the board. And one was when there was a union vote--the SEIU Local 250 came in not too long after the work stoppage. They were brought in by some people who wanted to try and help CIL, fix its problems: paychecks were getting late and there was a sort of an internal code system--if you could wait for your paycheck then that was helpful, and if you could put it off for a month that was more helpful and if you could wait indefinitely this was good, too. [laugh] And it created a lot of tension.

O'Hara: It did.

Lester: Yes, yes, it definitely did create a lot of tension. And people felt, and correctly, that we should be paying staff people before we were paying the rent or anything else.

O'Hara: Who made those decisions to pay rent, staff, and IRS in that order?

Lester: Phil. Phil and Rafe Taylor, who was the comptroller.

O'Hara: Meanwhile, did business proceed more or less as usual through all of this turmoil and strife?

Lester: Yes, strife was just sort of a part of life. It did get to the point where Phil and I were, we were working very closely together and we began to not be able to appreciate good news. When a grant came in, it wasn't this, "Oh, this is fabulous! We worked really hard, we got this together, congratulations to the people who wrote it, or everybody who was involved in it." It became at a certain point the absence of bad news: so good news was just judged as "Oh, great, it's not bad news." [laughs] Which is no kind of way to live. But there were some tough years in there where we learned some very hard lessons.

O'Hara: Do you have any other recollections of the board that you think we should include in our history?

Lester: When the union people came in and the union was actually voted in, it was pretty obvious that it had been a--the able-bodied people on staff had voted in the union. And I remember Chuck Cole, who was on the board at the time, coming to me and saying, "We want you to negotiate the union contract on behalf of management." Now when the lines got drawn about who was management and who wasn't management, we got some very poor advice and basically, just about everybody wound up on the non-management side except for like three or four people, or maybe five, but I was one of them. And they had also gotten some advice that they didn't want Phil to participate in the union contract negotiation because he would be seen as having the power to make an ultimate decision, and of course I had no power to make any decisions. The board wanted someone who would have to go back and get approval for any decision from the director and the board. So I finally said, "Okay, I will work on this but I will not do it alone. There is no way I am doing this alone."

O'Hara: Who did you do it with?

Lester: Well, Joan Leon was going to do it with me and then it was right at that time that she left and went to Sacramento because Ed had been lobbying Joan to join him in Sacramento and work on his staff there. She had resisted for quite some time and then finally decided it was a good idea. So Phil did it with me after all.

O'Hara: Was the introduction of the union idea an easy one at CIL? Was that resisted by some, or generally accepted?

Lester: It was generally accepted because we were in Berkeley and because the political climate and the general feeling about unions was so receptive.

O'Hara: Why do you think that the non-disabled staff supported it and the disabled staff did not?

Lester: That wasn't cut-and-dried straight down the middle, but by and large that's how it was. And I think it was about ownership of the organization, in part. I think there was a stronger commitment on the part of people with disabilities and also--well, that's not entirely fair because everybody was committed to the organization, but I think maybe there was less faith in the union structure. I'm not sure, but I think the able-bodied people were more fed up than other people were.

O'Hara: Why would that be?

Lester: In part, it might have been--most of the people on staff at that point with disabilities were on SSI, so they had other means of support, albeit subsistence, but they did have other income. And the able-bodied people by and large did not. And that might have contributed to it. I'm not sure.

One of the union reps had a daughter with cerebral palsy, they specifically brought him in to organize CIL for that reason. At one meeting I attended, one of the union reps said they were going to help us bring in more money, you know, to alleviate some of our financial problem. I asked him how many people they represented. They represented thousands of hospital workers in the northern California region and I said, "Well, now, what are you going to do when we're in competition for funding with other groups that you represent? Like the people at Alta Bates?" And he said, "Oh, well, that won't happen." And I said, "Excuse me, but we have departments at CIL that are in competition with each other over pots of money and funding sources and we've got different departments that want a grant from the same source and we have to make those decisions." Next question. [laughter] I actually think he went so far as to say, "Well, you obviously know what you're talking about. Next question."

O'Hara: [laughs] He said, "You obviously know what you're talking about?"

Lester: Yes.

O'Hara: When a unit or an activity at CIL ran out of money, when there wasn't a next grant for them, what happened?

Lester: You know, it's an interesting question. [pause] We laid people off. You know, I'm trying to remember when that happened and I remember things like VISTA [Volunteers In Service to America]. We had a VISTA grant and it brought in some folks to start deaf services and that's how we got deaf services going. There were a couple of young people who were deaf who started doing counseling and then when that funding was expiring, we found other money to do other things related to deaf services. So there was a lot of that--looking for other pots of money, sometimes redirecting people's energies a little bit. One of the things that nonprofits always have to do is create new projects for funders, or at least the appearance of something new that they can claim and put their name on. Sometimes you end up really doing something different and sometimes you end up recording, you know, tracking other information or gathering other statistics or doing something differently enough that it's acceptable, but you still get to do essentially what you wanted to do to begin with.

O'Hara: Well, does that--were there many layoffs in the seventies or mostly was there more shifting and deficit spending to accommodate the staff?

Lester: Well, we did get away from deficit spending. But once we got that under control and avoided further deficit spending, we also had a better system for tracking exactly what was happening.

O'Hara: Now when did the deficit spending end? You said it was recognized by early '76?

Lester: Right. Well, I'm pretty sure that that whole work stoppage--right after that--I mean, the board did make the point: we had to stop deficit spending. And our point was not that we didn't want to do that, the point was that we felt it was the responsibility of the board to govern and the staff to manage and it was a management decision about how to do that. And so it was right after that that we did cut expenses enough to stop deficit spending, and it involved some layoffs, and it involved curtailing other expenses. The details on that are gone, but over the years there were layoffs and there were projects that stopped existing when funding ran out. Basically, the only non-grant funding, aside from individual donations that largely came in through Friends of CIL, was the money that came in from wheelchair repair and that was all fee-for-service money. There was OJT [On-the-Job Training] money, which wasn't specifically grant money. That on-the-job training money was largely from Rehab; it was Rehab counselor controlled money: an individual would come on staff and we would train them and Rehab would pay their salary.

O'Hara: And that would be for people with disabilities?

Lester: Right. And actually a lot of people came on that way. But the real problem with that was that the OJT shift only lasted so long and in doing it to begin with, we were making a commitment to keep the trainee on staff after the training period, which we tried desperately to do.

Start of Computer Training Program

O'Hara: Was CTP--Computer Training Project as it was called then--one of your more vivid memories as a start-up, spin-off?

Lester: I remember back in October, November '74, Neil Jacobson and Scott Leubking were coming to CIL, meeting with Ed and with John Velton of the Department of Rehab and a couple of men from IBM and coming up with this idea. Rehab funded it from the beginning and I think they used block grant money to do it. I think the first computer class started in '75 and we rented an office around the corner at 2020 Milvia, which was the green and glass building where Vista College is now.

O'Hara: Around the corner from what?

Lester: From CIL, this was when CIL was still at 2054 University Avenue.

O'Hara: Neil and Scott founded the organization?

Lester: Yes.

O'Hara: In conjunction with Ed and John Velton.

Lester: Right. And IBM played a key role. Karen Topp [Goodwyn] was also around a lot. She was a Rehab counselor and I think she was--I don't know if she was Ed's counselor at that time, but I think she was Neil's and/or Scott's. She was the Rehab counselor for a lot of people who were involved in CIL at that point.

O'Hara: What was the purpose of CTP?

Lester: To train people with disabilities to be computer programmers. And in 1975, this was a new concept.

O'Hara: Was this exciting for everyone, even those of you not directly involved?

Lester: Yes. It was pretty exciting. I think it was a little bit abstract [laughter] for a lot of people. And it was also in that

nerd realm, you know? So it was like, "Okay, well, they're off doing this thing that they're doing." It was very exciting--there was a strong feeling that it was ground-breaking, but by virtue of the fact that it was around the block, there was separation pretty early on.

O'Hara: Not too long after that the Disabled Children's Computer Group started, didn't they?

Lester: Well, DCCG started in 1983.

O'Hara: Oh, '83. I remember parents meeting in the mid-seventies, but it wasn't a program, I guess.

Lester: Yes, not until later. Yes, in fact, DCCG came along when the PC was brand new, and it was an Apple computer--Apple Plus, Apple II Plus, which had 64K memory, green screen--

But these guys [at CTP] were working in the main frame world. So a lot of the contribution of IBM was for time on their terminals and it was definitely revolutionary.

O'Hara: And did the students get employed when they finished the program?

Lester: From the very beginning there was a business advisory committee that included IBM. They involved the business community from the very beginning to make sure they were training people in what the industry wanted people to be trained in. And they set up a job placement service as part of the program from the very beginning. The placement rate was always very high. It was well over 80 percent as I recall if not 90.

O'Hara: I think it was, yes. Closer to 90, 95.

Lester: Yes. So they really did do it right. They got the right people involved at the right time and with the right idea.

O'Hara: Now were Scott and Neil instructors?

Lester: Scott and Neil were the instructors but they were also the administrators.

O'Hara: For how long?

Lester: A number of years. And I think Neil did more administrating than Scott. I think their natural tendencies went in different directions. I wasn't involved in the daily workings of that at all. In fact, the program was always fairly separate.

I was involved when they had a secretary in the beginning who was part of the CIL family--actually it was Lee Ann Kurtz who later was involved with Michael Pachovas. I think she might have worked at DSP [Disabled Students Program], I'm not sure. Anyway, she was part of the scene and then she left and an old friend of mine, Terri Davis, was hired to be the administrative assistant and fill that support role. And she later, several years later, actually became the administrator of the project.

O'Hara: Oh, really? I see. And when did Joni Breves come on?

Lester: Joni came on--Joni was hired as the student assistant--I'm trying to remember what it was called--but basically Joni was hired to facilitate students as students. She was there to provide the support services and make sure they had what they needed to succeed in terms of tools and support services and all of that stuff. I'm pretty sure that that was the role that Joni played early on. I even remember Joni's interview; [laugh] she likes to tell this story a lot. She was concerned about what to wear and she tells the story that I was wearing this t-shirt that had two pigs kissing.

O'Hara: [laughs]

Lester: And I keep trying to convince her that it was a dog, and it wasn't kissing anything--the pigs weren't initially kissing when she first told the story but as time went on--

O'Hara: And what was she wearing?

Lester: I can't remember, but I suspect that she was significantly more dressed up than I was, at least in the interview.

Separation of Computer Training Program from CIL

O'Hara: Do you recall how CTP separated from CIL?

Lester: You know, I don't. I remember that the decision was made and it involved Phil and Neil and the board. And it was incorporated separately as a 501(c)(3). I think their main motivation was they wanted to be able to control their own money. And they needed to. It was the right decision.

O'Hara: I understand that DLRC [Disability Law Resource Center] wanted to separate for the same reason. Is that your understanding?

Lester: Yes, basically.

O'Hara: Was that a smooth separation?

Lester: Yes, I think it pretty much was. I remember not being involved at all and sort of being informed with the rest of the crowd that they were doing that. I think it was basically a good decision. I think spinning off was a right decision for most of those programs. Programs reach a point where they need to be able to raise money beyond what they can do as part of another organization. And also, most of those programs were run by very strong people, and leaders need space to lead. So it was a natural progression of things. I think some groups came on specifically with the intent of doing that at some point--using CIL as a way to get seed funding and then going independent.

O'Hara: For instance?

Lester: Well, I always saw BORG [Berkeley Outreach Recreation Program] that way, but BORG was less connected with us than some. And I could be wrong about that, but I think BORG was already established and then got some funding and wanted to be a part of--CIL was always kind of separate. I'm not sure about DLRC and what the initial motivation was but I think pretty early on it probably became clear that that would be the way to go. I don't know. It's easy in retrospect to say it was a right thing to happen and it happened in a good course of time.

O'Hara: When in the seventies did CIL reach its peak of fame and symbolism?

Lester: I would think probably in the last couple of years in the seventies, like '78, '79. And it happened, I think, around the fact that there were a lot of CILs springing up. Over the years we were contacted constantly about how to set up an organization like it. Then there was the money that the state set aside through the Department of Rehab for funding for independent living centers. I'm looking to see if it's here on the list--I think that was a real turning point. It was sort of the point at which the independent living movement was recognized as legitimate, legitimate enough to be funded. I also think and I've talked to people over the years about what happens when the organization you grew up in reaction to turns around and funds you.

O'Hara: You're talking about the Department of Rehabilitation?

Lester: Yes--[laughs]. And the fact that CIL from the very beginning was always biting the hand that was feeding it and CIL created this, I think, very productive tension for a while.

O'Hara: You mean the one hand, Rehab, or other sources?

Lester: Well Rehab, most notably, was the hand that was getting bitten.

O'Hara: Why did they create it?

Lester: Because I think we were able to use the system to model better behavior, and to demonstrate how we thought people should be served, and who should be serving them, and we got away with it. And I think we got away with it because we were novel and we were pretty high profile.

O'Hara: Was there any open opposition from Rehab?

Lester: Well, I think there was certainly open opposition to Ed's becoming the director of Rehab. That I remember. And I think we sort of suffered in that backlash. There was also--when Ed went to Rehab, there was the notion that we would be able to get all this funding to do all this stuff that we wanted to do. And in fact it was quite the opposite, because he got to Sacramento and even the appearance of conflict of interest was so strong that he basically wasn't able to do anything for CIL. The whole time he was there, as I recall. But he was in Sacramento when the funding went through the state--A.B. 102 or something--that funded independent living centers, so he was certainly able to move the agenda that way, and was successful at it.

III INNER WORKINGS OF CIL

[Interview 3: April 28, 1998] ##

Personnel Policies, 1976

O'Hara: You're having a look here at the CIL personnel policies that were written--does it have a year on it?

Lester: It doesn't have a year, but it would have been 1976 most likely. 1976 or '77.

O'Hara: It's extremely detailed, it looks like it's about eight or ten pages. And I read through it, down to the last holiday; everything is included in this personnel policy. Why was it so detailed for such a small organization?

Lester: Had they been written when the organization was small, they probably would have been a lot less restrictive, but we had gone so long without any rules at all and had so many employees by that point. We must have had probably seventy, seventy-plus or close--certainly more than fifty staff--and we didn't have any personnel policies. So the board formed a committee: I was on it, Hale Zukas was on it, and there were some other people from the board and staff--I don't remember how many people. We started with some examples of personnel policies from the City of Berkeley and the University of California brought to us by CIL board members. So we already had an outline, theoretically, that we were following, which is why I think they were so extensive and they take in so much territory. They were really written very much to protect the staff and not to protect the organization. Looking at them now--and it starts: "Violation of Rules"--they're so heavy-handed. They really were not intentioned that way at all. In fact, later, when the issue of the union came up, people felt that these personnel policies were much more protective than those governing other organizations represented by unions. And we have more holidays and more vacations than many other unionized employees.

O'Hara: Well, why did the staff feel they needed protection?

Lester: We didn't think the staff needed protection, but they were written from the perspective of getting maximum involvement of staff in the workings of the organization: in hiring and firing and things like that. They were designed to include as many people as possible. People would have say in who was hired and who they were working with, and protected in the sense that the termination policy was very arduous. There was a whole set of requirements--you had to have meetings, and notices, and writings, and files and--

O'Hara: [laughter] The Court of Appeals--

Lester: [laughter] And that was done to try to be as fair to everybody as possible. Well, in doing that, I think we left the organization with not a lot of flexibility in terms of what it could do in a situation. Certainly now you would never see nonprofit personnel policies written in this way.

O'Hara: When I read it I thought maybe it was a reaction to some--to maybe a serious lack of order?

Lester: Well, there was--I wouldn't say a serious lack of order, I would say there weren't stated processes and procedures, and so everything was done on a case-by-case basis. I think there was a desire on everybody's part for more methods and mechanisms so that we didn't have to do everything on a case-by-case--so that people knew what the boundaries and the rules were, and every issue didn't have to be taken to Phil or Judy. There were other ways to go. A lot of this was written because we were doing so much hiring. We were funded heavily by the city, the county and other government agencies; there were a lot of rules at that time about affirmative action and notifying the public about job openings. You couldn't just do an internal hire when you were hiring somebody onto a grant, at that time, anyway. There were expectations that you would do a lot of mass mailings and open hires--so a lot of it was written because of that. We did certainly have our share of personnel problems and dismissals and things of that nature that we needed rules for. I think a lot of this was written before we needed it, but we wanted it to be there. But like I said, we were pretty big already by the time this got written.

O'Hara: We'll definitely have to have a copy of that or the original in the Bancroft file.

Lester: Absolutely. [laughter] A must-have.

Complex Revenue Streams

O'Hara: The other document that you gave me to read was the list of the funding streams, I think it was in 1977. And it was an incredibly complicated set of funding streams. Some of them lasted three months, some of them lasted six, some eighteen. And many were just partial coverage for certain positions or certain programs, and they're so many of them! How in the world did you manage this?

Lester: Well, it was very complicated and in fact, we didn't even start really managing this until about 1977. We got a grant from the Rehab Services Administration to computerize CIL, its accounting systems and record-keeping systems, and to set up an office of grants and contracts administration so we could begin to get a handle on everything, because by that point we were actually quite large. As you can see from this other report, which is the "Government Grants and Contracts from 1972-1979," it paints the same picture. We had multiple funding sources and we had departments covered by multiple grants: one person in a department would be covered by one source of money and another person would be covered by another source. So you had two sources covering bits of departments, you had sources covering multiple departments like in the case of the Alameda County Revenue Sharing; that covered a lot of direct services such as attendant referral, but it also covered wheelchair repair and so it was quite complex.

When we opened the office, Bette and I were hired to do the grants and contracts administration and we divided things up by source. She handled most of the government grants and contracts--the federal government--and some of the state Rehab grants, and I had some other state Rehab grants and I had the City of Berkeley and, I think, the County of Alameda. We sort of did it that way. We were getting CETA funds, we were getting block grant funds, and we were actually very, very successful in those years in getting--

O'Hara: Well, it looked like everybody wanted to get on the bandwagon?

Lester: Right. Well, we were very unique for a great many reasons. We were doing a lot of new things--we had talked earlier about how new services and departments got added and a lot of it was because of very creative people coming in the door and saying, "This is something that I would like to do that I think is an important service. And let me work on the grant and if it gets funded, let's work on it together." There were a lot of things like that. Like Peter Leech's project, very early on, the training project, that I believe was funded by the Department of Rehab where they

had people come and take on the role of living with a disability for a week.

O'Hara: What kind of training is that?

Lester: Well, it was training for counselors who wanted to work in the field of disabilities. And I remember actually there were a couple people who came to work at CIL who went through the training. Jim Pechen, I recall, went through it and he had been hired to work in DPLRC [Disabled People's Legal Resource Center, which became DLRC], I think. And Larry Herring was another one; he was hired in development and he went through it. And I think he lived with Don Berry for a week and had to basically function using a chair and experience what the world was like. There were other disabilities involved as well--I think they did some training involving vision loss.

O'Hara: People actually lived and shared an apartment with somebody.

Lester: Yes.

O'Hara: How long did that go on?

Lester: In most cases I think it went on a week. Maybe not every case.

O'Hara: Wouldn't that get a little bit old for the people who were sharing their apartment?

Lester: Well, yes. Some people did it--well, they got people in the community and people who worked at CIL to put these people up, so there was an agreement. And initially it was great fun, you know. Everybody thought this was really different and interesting. And yes, it got thin. But the grant as I recall didn't go on for all that long. But it was definitely a different and unique project and that's just an example of some of the stuff that we did, that we had funding to do.

Demographic Profile

O'Hara: Let's talk about demographics for a little bit. Were there representations of various ethnic minorities and a variety of ages and disabilities on the staff, or was it predominantly one color or one disability?

Lester: The organization was always accused of being, figure the term, "quad dominated." This I heard from a lot of people with visual

impairments. The majority of people with disabilities on the staff did use wheelchairs. Blind services was a very small department and there were at any point in time three or four people with vision impairments on staff, I think. But there was always an effort to seek out employees--people of color and different backgrounds. I think one of the things that I gave you was the affirmative action policy. As a grantee of the City of Berkeley, we were required to have an affirmative action plan. And one of the things that we did was a survey of the breakdown of everybody on staff and I remember that there were always more Caucasians on staff than anybody else, but we made a lot of effort to try to find people of color.

One of the big things we were up against was convincing the City of Berkeley that people with disabilities were a minority and that they counted in affirmative action statistics. We were always making the case--CIL was a services organization and also very much a training organization, and it's very difficult to do both, especially to do them well. And one of the main things we tried to do was provide job opportunities and training opportunities for people with disabilities. At that time the vast majority of disabled people were not out in the world, and didn't have opportunities, and had a long way to go in terms of developing job skills. That was true among Caucasian people with disabilities and it was even more true among African-American people with disabilities and other people of color. And so it was a real challenge for us to find employees that would fit all those categories. We made every effort possible.

O'Hara: Why was it such a challenge? I mean, why was it so difficult to find other than white employees?

Lester: Because I think they were further back in people's closets. You know? A lot of the people we were serving, especially in Oakland, were living in their parents' back bedroom up three flights of stairs. The culture and consciousness around disability just was very different.

O'Hara: Among different ethnic racial groups?

Lester: Yes. Also resources were much more limited, so people didn't have wheelchairs. People didn't have dollars to buy ramps, people didn't have dollars to adapt their cars, or anything else.

O'Hara: What about the balance between men and women? Was there a balance, or was there any noticeable imbalance?

Lester: I think it was pretty balanced. I know a lot of women felt that there was a lot of sexism at CIL in the power structure. I think

--well, there were a lot of women who had a lot of influence at CIL. I think probably if you went down the list of managers, there would have been more that were male than female over the years.

O'Hara: All of the directors of CIL, except for one, have been men.

Lester: Right. That's not a surprise. Was there a female executive director?

O'Hara: Marilyn Thornton.

Lester: Was she there long as the director?

O'Hara: No. And why is it not a surprise? To this day--now?

Lester: Yes, it's interesting. And for some reason it doesn't surprise me. Why--I don't know why. But I would say, also, if you looked at the board--now I'm guessing here, but in my memory probably the majority of board members, at any point in time, were male. I remember Debby Kaplan at one time was the president of the board so I know that there have been female board presidents, but I bet that far more of them have been men.

O'Hara: Do you think this is just a reflection of the general society?

Lester: That's an interesting question because predominately people in nonprofit organizations--in my experience, there are more females than males. One of the reasons is because they don't pay as well, it's long, hard hours, and it's social services and it tends to be female dominated. But this is a different world, the rules were different, everything about it was not according to the norm. And, yes, it probably has something to do, also, with the fact that the unemployment rate among people with disabilities is so high and that they're just--

O'Hara: Men and women?

Lester: Men and women. And that there are not really the opportunities, especially then, that there are, you know, for the rest of the population.

O'Hara: What about ages? Obviously there wouldn't be children working there, but were there people that were older, elderly?

Lester: Not really. When I started I was one of the youngest and I was in my early twenties and I remember Phil and Ed were both in their mid-thirties.

O'Hara: Was that kind of the general age group?

Lester: Yes, the age group was basically mid-twenties to mid-thirties. And there were--Peter Leech and Janice Krones, for example, who were older than that and there were a couple of other people, but primarily not. We did hire one gentleman who was in his mid- to late sixties later on, but he was the only one in my tenure.

O'Hara: A number of people have remarked that there seems to be a fairly large number of gay and lesbian people in and around the disability movement and at CIL. Is there any accounting for that?

Lester: That's a really interesting question and it's true, we had a high percentage of gay and lesbian people on staff. I think there's an acceptance of people in general in the community that is higher than elsewhere.

O'Hara: In the disabled community?

Lester: Yes, I think people are just more accepting and open to differences. It's just sort of the nature of things and I think they're much less likely to discriminate and criticize and expel people for being different, especially in Berkeley.

O'Hara: So, it made it a more comfortable environment for people who are gay or lesbian.

Lester: I think so. Yes.

O'Hara: Now, you mentioned that there were quite a few wheelchair users and there were some blind employees. Were there other types of disabilities among the staff?

Lester: In 1977 we got a VISTA grant and opened deaf services. Actually, Dale Dahl--was a gentleman--he was a wonderful soul who was really pushing to bring deaf services in and to bring in services for people with multiple disabilities, which was something we really hadn't dealt with. Dale was someone who was deaf and had broken his neck in a car accident, so he was using a power chair. He tried to bridge the two communities and was very instrumental, I think, in getting deaf services started; as was Judy, who was really the mover and shaker behind that.

O'Hara: Was Judy the first to begin deaf services?

Lester: Yes. I think Dale was on the scene--I think he was one of the people behind it, one of the first people to show up and really support it. It was something that was done when Judy came on board; it didn't exist before that. Judy was really pushing for

expanding the service population to include people who were deaf, to include people with developmental disabilities, mental retardation, and emotional disabilities.

O'Hara: I think--we talked about that before--did you say that that never really became a reality?

Lester: It didn't in the period that we are talking about. I mean, there were people who were sort of otherwise part of the target group of CIL, used a wheelchair or had some physical disability and also had some other issues, people living on the streets. Because we were right there on Telegraph Avenue, we attracted a lot of people in the neighborhood that were otherwise maybe just homeless. There were people coming to us for service that we really weren't quite skilled enough to deal with--some issues that really went beyond our capacity, and I think Judy was trying to build that capacity. I don't think, up until '80 that we ever really succeeded. We didn't have any funding or any sort of planned program for it. It might have happened later. I know that also at that point we weren't really serving people under the age of eighteen, particularly. There was a project that was funded by the Bureau--it was then called Bureau of Education for the Handicapped, BEH, and it was the KIDS Project which was about working in schools to do disability awareness in regular classrooms where kids were being mainstreamed. But we weren't really providing any services for youngsters--it did come later, but not in the seventies.

O'Hara: Given the differences that did exist in the staff, racially, and male/female, and sexual orientation and types of disability--was there any tension on the staff among any of those groups?

Lester: Yes. Well, there's a lot of tension in general, certainly in the later seventies, that had to do with not having enough resources, paychecks being late--I mean there was a lot of tension that had grown around a number of issues. As I said, some people had expressed to me the fact that they felt there was a lot of sexism in the organization. I really can't speak to how a lot of other people felt, I can just remember what I heard and what I felt, myself. I think there was a dynamic setup between people without disabilities and people with disabilities which allowed the union to come in. I think the union came in because paychecks were late, there weren't enough resources, there were some real problems going on, and it fueled some other problems. I don't think it was resentment back and forth but I think when there was a vote--it came down to one side versus the other. At one point, somebody proposed that the membership of CIL, the body that elected the board of directors, consist of two classes of membership: the voting class and the non-voting class. The voting

class would be people with disabilities and the non-voting class would be people without. [laughter] This suggestion lived about five minutes as I recall. [laughter]

O'Hara: I remembered hearing that there were various caucuses at CIL--the women's caucus, for example. Does that ring any bells?

Lester: You know, it doesn't ring a bell.

O'Hara: Well, you were there.

Lester: It might have been later. I certainly don't remember any meetings happening. And of course, there would have been multiple meetings.

O'Hara: What do people mean by sexism? How was it manifesting itself?

Lester: Well, I think people felt that most of the decisions were being made by men and they didn't feel they had a say, as near as I can remember. You know, there was--the dynamic between Phil and Judy was an interesting one because I think in some ways they sort of functioned as co-directors and in other ways they really didn't.

O'Hara: Let me flip this tape.

##

O'Hara: What, in general, was the political leaning of the staff? This was in the seventies, it was right after the hippie sixties and Berkeley was certainly very hippie.

Lester: Berkeley was very hippie and very open and very, you know, democratic and left-leaning. And so was everybody who showed up at CIL.

O'Hara: Pretty much across the board? No exception?

Lester: There probably were, but they wouldn't say.

O'Hara: [laughs]

Lester: So if there were Republicans or right-leaning tendencies, they were strictly in the closet.

Attempt to Start Oakland CIL with Black Panthers

O'Hara: Did the fact of diversity on the staff--because it's obvious it wasn't all one group and all one disability--did that make any contribution to the CIL operation?

Lester: I think it made a tremendous contribution. I also think the philosophy of the organization, which was about people coming together to create a better system to meet their own needs that could best be described by themselves--a very inclusive philosophy--was at the very heart of what CIL was all about. And it was about including everybody. A story that comes to mind is when Ed made the connection with the Black Panthers to open an office in East Oakland.

O'Hara: Did that actually happen?

Lester: It did happen, indeed, it did. It was never very successful. And Brad Lomax was the guy that was hired and a woman who I believe was called Arlene--I can't remember that really well, but there were two people who were stationed in East Oakland. I think they had a storefront and they were providing basic services.

O'Hara: Do you remember where that was?

Lester: I don't. I never visited. Ed visited.

O'Hara: What kind of services did they provide?

Lester: Well, I think they were just doing the basics of peer counseling, and some attendant referral, and maybe some housing referral, but it was very small. And it was really at a distance, which was one of the problems in terms of its being successful. Also, you know, CIL wasn't at all familiar with that culture or that community and they sort of plunked this thing down and really didn't understand how to make it work very well, so it was fairly short-lived. It was just another example of some of the stuff that we tried to do. My understanding is that there is now a branch in Oakland. I think it's in West Oakland near downtown somewhere. When Tony Compton, my partner, and I were living in Oakland, he contacted CIL to use their services.

O'Hara: I think on Eighth Street, if I'm not mistaken.

Core Philosophy

O'Hara: Well, now, you made reference to a core philosophy of CIL. Did the staff, in general, all hold to that philosophy of inclusiveness? Well, let me ask you: when you were talking about the heart of CIL--to make it possible for each individual to be included in society--and there's probably more to it than that--would you describe again the core philosophy, and then comment on whether the entire staff felt the same about the core philosophy?

Lester: Okay. I think you're right, the core philosophy was broader than the way I just described it. It also had to do with making the world more hospitable--making the environment more hospitable, controlling the environment and making it be what people needed it to be. It was about people with disabilities controlling their own lives, and making their own choices. So it wasn't just about bringing people together to do a better job than Rehab was doing, for example, at providing service, it really was about trying to change the larger environment and the system and the world in which people were living. And I think people did agree about that, by and large.

The problems came in when you looked at how best to do that. As in any organization, everybody's going to have different ways of looking at that. I think, also, that in the early days there was an excitement and a newness about it all so that people coming into it got that fever, got that understanding, had a sense of the energy and excitement about doing something new and really breaking ground and doing it together. And that was lost over time as the organization became larger, which I think is natural in the evolution of a nonprofit organization.

I think there's a critical mass that a lot of organizations experience; once you get beyond a certain size, you lose a lot of the benefit of a smaller organization in terms of people being able to communicate with one another, having the time and the energy and a common understanding. That's lost when an organization gets more structured, more rigid, and bigger. Labor is divided more rigidly and people have very specific tasks and begin to know less and less about what their fellow employees are doing. I think it's just the nature of the beast. So in the beginning I would say there really was a common feeling of energy and excitement and shared philosophy, and I think it lasted fairly long. And a lot of new people coming on brought their own energy to it and so it changed and evolved, but a lot of it continued on.

O'Hara: Would that be through the seventies do you think?

Lester: I think so.

O'Hara: This volume--Joan Leon brought that over--it's the "Oversight Hearings of the Rehab Act" of '73, and I thought '76, which were held at CIL. People's statements at those hearings sounded like they were pretty together and pretty excited about what had already happened in the first five years of CIL.

Lester: Yes, especially to the outside world: the message to the outside world was very strong and very energetic. And there was a lot of --for lack of another word--solidarity about what was happening.

Unspoken Problems

O'Hara: Were there things that weren't spoken publicly?

Lester: Initially there were, like our debt to the IRS and some of the things that were making it very difficult to maintain harmony. We had grown very fast, as we've talked about before, and the infrastructure wasn't there to support it, so, yes, that was the stuff that began to eat away at the common feeling of well-being. Morale is something that I believe ties to two things. One is the way people communicate, interact and relate to each other on the job. The second is how they feel--how secure they feel, how good they feel--about the overall health of the organization and the direction it's going in. Both of those things are very important.

We had some problems with the second one for sure, but there was still a tremendous amount of dedication and commitment on the part of staff. A lot of people put in a lot of extra hours, and then there were people who would just come and take advantage of the situation, which is do a nine-to-five job and do it well, or not do it well, you know. There was a tremendous amount of freedom because in spite of the way the personnel policies read, nobody was heavily supervising anybody else. There was a lot of expectation that people would work on their own initiative and be highly motivated, and some of that was well founded and some of that wasn't.

Excitement and Optimism

O'Hara: You said earlier, when we weren't taping, that this was some of the best years of your life. Did other people, do you think, feel

the same way? Was there a general excitement and optimism? What was that?

Lester: I think there was a lot of excitement and optimism. It was a very fun place to be for a long time. There were some fascinating people that would just come and gather and chat and hang out. It was also an exciting time in Berkeley. There was a lot of energy, and as I said, the vast majority of people working there were in their mid-twenties to mid-thirties and there was a lot of stuff that went on that wasn't part of the job: people came together, there was a lot of socializing. We had incredible Halloween parties. We did stuff that just went above and beyond--because we wanted to and because it was fun as a group to come together. And it was very unusual as an organization to just party, in a way, but that was providing opportunities for people who never had a chance before to go to a great party because transportation was a problem, or this was a problem, or that was a problem.

A few of us used to go on camping trips together, just sort of impromptu. I remember one where we dragged Phil Draper and Don Berry out on to the beach--we dragged their power chairs and got them stuck up to their hubcaps in sand, then the wind shifted. All the smoke from the campfire started blowing right in Phil's face and we had to drag him around again. There were a lot of social connections between people on staff. There were a lot of roommate situations, a lot of people on staff were seeing other people on staff socially, and so there was just a lot of stuff going on that made it a very interesting and amazingly fun place to work. An informal analysis conducted by a couple of us determined that of the seventy-five people on staff at the time, twenty-five of them were sleeping with each other. There was a lot of sex and drugs and rock and roll.

O'Hara: What about the idea of the work, itself: was there a sense that you were a part of a movement?

Lester: There was. Some people had more of a sense of that than others, and some people had the smaller picture of that and some people had the bigger picture.

O'Hara: How about you?

Lester: I had a sense that we were doing something very unique, that we really were--for a whole variety of reasons--creating a new model. But what surprised me later when I turned around and looked back was that there were, suddenly, hundreds of organizations in the country calling themselves Centers of Independent Living. I realize that there were--at the same time this was happening in Berkeley--there were similar things happening in the rest of the

country. I've heard from other sectors that people sort of resent the fact that CIL has claimed all the glory for being the first one, but to be fair we weren't the only people doing it. There were other communities that were getting things together. I think it's really interesting that the label, Center for Independent Living, has been used so broadly and also that there are so many. In a way it makes me sad that--well, I've had some experience in recent years with some Independent Living Centers. I've had occasion on behalf of my elderly parents to look for services in northern New Jersey and been very disappointed at what I found and how difficult it was to find things; but every community's different. As far as CIL, though, I really did share this feeling that we were doing something very, very unique; I didn't have in my head that we would then be replicated all over the country and it would be funded by the Department of Rehab. That surprised me.

O'Hara: When you say there were other groups in the country starting to do things like this, what are you referring to exactly? Were there other centers for independent living that you're talking about, maybe doing advocacy?

Lester: Well, what I've heard is that there were other organizations of people with disabilities coming together and doing services and stuff. I don't know a whole lot about this. June Kailes is somebody who has mentioned this to me. We've talked a little bit about it and she is way more familiar with the history of the movement than I am, certainly after 1980.

O'Hara: Why do you think Berkeley became so famous? It certainly always is mentioned as the first, whether it was or not.

Lester: Well, I think a lot of it had to do with Ed and the fact that he was very politically savvy and built notoriety--and I think he did it very deliberately. Judy's presence made a tremendous difference because she is also so politically savvy and was operating on a national level to really raise the organization's profile in a very significant way. I think the 504 demonstrations catapulted CIL into the limelight in a big way, even though we weren't the only organization involved in that; it was a great coalition of groups all over the Bay Area. But because a lot of the leadership for that came from CIL, it had a major impact. I also think the work that we did--and I wasn't a party to any of this--this, again, was Judy and Betty who worked on getting the funding through the Department of Rehab to set up independent living programs up and down the state.

Founding of Independent Living Center in San Francisco

Lester: That was actually at the point where work began on getting the independent living center in San Francisco going. This would have been probably toward the end of '77, the beginning of '78, something like that. There was state legislation that funded these programs under Rehab funding. And Ray Uzeta, who was the head of the transportation department at CIL, asked me if I would join the California Association of the Physically Handicapped to help him write a grant to start an independent living program in San Francisco. I was living in San Francisco at that time and I said, sure, I would do that. And so we began work on it and--CAPH was a 501(c)(4) organization, which means it was an advocacy group: it was more political than not. So, we were going to set up a 501(c)(3) nonprofit organization as an independent living program under the auspices of CAPH.

And the Department of Rehabilitation said to us at the time that we had to collaborate with United Cerebral Palsy, the San Francisco chapter, because they also wanted to set up an independent living program and that they wouldn't fund either one of us unless we worked together. So we did, we submitted a joint application but it went in under the legal status of UCP.

O'Hara: Oh, it did?

Lester: I was also part of that.

O'Hara: This is funding from Sacramento? And did it get accepted?

Lester: It did. So UCP set up an independent living program. And from the very beginning it was a difficult relationship because CAPH was a consumer organization and UCP wasn't really. There were a few people with disabilities working at UCP and involved in UCP, and there were some people on the board, but it wasn't really a grassroots, consumer-based organization which CIL had been very much. The fact that CIL was consumer-based and grassroots was what made it so successful. It was at the heart of everything. Anyway, I served on the advisory committee for the UCP independent living program for a couple years along with Michael Winter and Paul Bendix and some other people that [laugh] probably you would know if I could remember their names.

O'Hara: Michael Winter or Williams?

Lester: Michael Winter, yes. And Ray Uzeta was the executive director of the independent living program, initially. I know it still is in operation and I believe it's completely independent of UCP.

O'Hara: Yes, I think it's been independent a long time.

Lester: I would think so.

O'Hara: The relationship with UCP didn't last, did it?

Lester: It was not a good recipe for success from the beginning. But when you have a nonprofit organization that takes on a project like that, that's potentially so huge, especially in terms of dollars and demand for service, it's going to completely change the original organization, or it's not going to survive, itself. I mean, it's just not anything that I've ever seen succeed. You get into funding concerns immediately. When you're taking on something that large and a source of funding becomes available, you've got to make hard choices about which department you're going to try and fund, or which service, or whether you're going to go after a new service. The competition, the questions, the issues, and the ethics get very complicated really quickly. Especially in a case where you've got a community-based advisory board and a board of directors that's responsible for the umbrella organization: it's a recipe for disaster. And I think they survived like that for several years.

O'Hara: Going back to the Berkeley CIL, was there much turnover in the staff?

Lester: People hung around for quite a while. People, when they got there, they liked it. It was a very good place to work for a lot of people for a long time. But people were young, you know, they were moving on. A lot of the people that worked there were part time and they needed to get full-time jobs and--a lot of people moved away. I would say that it was fairly average, although what's average? At one point we were one of the biggest employers in Berkeley, which was pretty amazing, especially when you consider that I don't know that we ever had more than 120 people. We might have had a little more than that but that says that a lot of the operations in Berkeley are very small.

Reasons for Survival

O'Hara: So, looking at all the things that you've talked about CIL, it still is in existence. What allowed it to flourish in the seventies and into the eighties?

Lester: Well, the environment was very receptive, certainly in the early seventies. We discussed earlier that county revenue sharing had

come along, there were a lot of foundations in the Bay Area--there still are--there are a lot of financial resources in the Bay Area, and a political tolerance and acceptance. I think there has always been in the Bay Area an acceptance of new and innovative ideas. And people are always looking for new things to support: in fact, the whole funding community is set up around new projects, you know. They don't want to fund existing things, they don't want to pay for operating costs, they want something new and exciting. And for a long time we were able to come up with some very new and creative and exciting ideas that other people weren't doing. There was, to speak of, no paratransit systems in existence in those early days--in the early seventies--so we were able to fund a fleet of ten vans. We were able to do things because there weren't alternatives: there wasn't a commercial wheelchair repair operation anywhere. And you know, initially we started that very small; we opened and people came. And the more people came, the more there was a need for it and eventually commercial operations did go into business and have been very successful.

O'Hara: Do you think it is important that the city is so densely populated? Or maybe I should rephrase that--the apartments in Berkeley are pretty close together and pretty close to CIL. Do you think that was a big factor, knowing what you do about other CILs?

Lester: I think it was. For the longest time, most of the people who came to us, used their own mobility, be that manual chair or power chair or whatever it was, so being in the center of things was very important because a lot of people didn't have vans. Buses weren't accessible (still aren't as accessible as they should be).

O'Hara: Was it serendipity, a particularly favorable group of people that came together at this point in time and place?

Lester: I think that was part of it. I think there are a few key people that made an enormous difference. And because of the impact they had, you know, they attracted other people, they created an environment that then attracted more people. I'm thinking of people like Ed, and Phil, and Hale, and Kitty, certainly in the very early days and then later, Judy. I think of Hale, for example doing all of that work to get the curb cuts in. Hale worked tirelessly with the City of Berkeley, picking out corners, making them do it, and checking the specifications and dogging it, really dogging it; and then working on BART so hard, to get BART accessible. And there were a few people with just such a passion and an energy that I think made a tremendous difference. And then I think the weather, no question the weather had an impact. The climate here is pretty good: it's not terribly harsh, it doesn't

rain as much as it does in the rest of the country, and it's easier for people to deal with.

O'Hara: It seems to me that the CIL community included a good number of very intelligent people who didn't have disabilities--yourself, Lynn [Kidder], Bette [McMuldren], for example. It's far more than you would ordinarily find, I would think, in a nonprofit startup organization.

Lester: That's probably true and--

O'Hara: And dedicated. I should say dedicated, also.

Lester: Yes, it's true. We were very dedicated. I think--there are a couple of factors that come to my mind. The University of California, Berkeley is not to be overlooked in all of this. The university had a tremendous impact: just being there for one thing, and the people that it brought to the City of Berkeley, a lot of them were involved in CIL in the early days. And Lynn and I were products of the university and stayed because we liked the environment and the culture. That was true of a lot of people at CIL at the time. Bette was in Berkeley because her husband was going to the university--you know, it played into things. And also the university was very supportive of CIL in the early days.

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O'Hara: You were talking about the university being one of the factors that aided CIL in flourishing.

Lester: Right, because of the impact it had on the organization and the community in general. And I think one of the other things that brought so many people together that were bright and dedicated was the nature of the times. We talked about this before, the impact of war on the generation that was emerging out of the university system and its expectations for something different than what had gone on before. We had a belief that things could change, that things could be different if you just worked hard enough and had enough dedication and energy and imagination. We could change the world. And emerging with degrees in anthropology as I did--and I believe Lynn's was in political science, and there were a lot of history majors and English majors--and all these people that had an understanding of zip, really, [laugh] in terms of reality and making their way in the world. In some ways sort of starting with clean slate and looking around for possibilities.

For example, I wound up at CIL, after working temporary jobs for about a year and a half after graduation, because I went to the university career center and the counselor had organized her

jobs in terms of profit and nonprofit organizations--as opposed to secretary jobs or engineer jobs. So I immediately went to the nonprofit sector and there was this organization that she didn't know anything about--it was called the Center for Independent Living and maybe I should go check them out. So that's how I found my way there. And Lynn found her way there through doing attendant work for Don Berry, and I think Phil--she was their cook. So there were a lot of people who had graduated or dropped out of Berkeley and were hanging around and just were trying to find their way. And they had a fair amount of intelligence--some of them had a great deal of intelligence, like Lynn--and were looking for something meaningful to do, and weren't going to settle for something that wasn't meaningful except just as an interim thing to put food on the table. Certainly, that's how some of us got there.

O'Hara: One of the factors of CIL's existence and its staying power?

Lester: Yes. Commitment can be contagious. I think people can get commitment from other people, build on it and grow from it--not always, but I think it is something that can be shared.

O'Hara: And then lastly--wasn't there a certain satisfaction that came from seeing a need fulfilled? I mean, you had people like me coming in there and this was a whole new world--it must have been very satisfying for staff to participate in that, to make it happen for people.

Lester: Yes, there was a very direct connection, even on the administrative side where I was, there was just such a direct connection with the outcomes because you could see it everywhere you went. You walked down the street and there were all these people functioning independently and going about their business and living their lives in ways that--you knew it had not happened before and was not really happening anywhere else at that point. There was just a very direct connection because everything about the organization was providing service, so even if you were just there to chat with somebody when they came in, it was part of what we were about. We were creating an environment that made people feel comfortable and feel like a participant in the community around them. We were just another important piece of that community that everybody was interacting with. And it was also very exciting to be in this world where everybody coming in the door was so different from anybody else coming in the door. You were constantly learning about somebody else and their challenges and their story and the way they viewed life, which was so different from anything that we had known, or I had known before.

Staff Names, 1974

[Interview 4: May 7, 1998] ##

O'Hara: I know that you want to go back to a few things. And one of them was the size of the staff in 1974. You wanted to mention the staff members?

Lester: Yes, I did. I came on board in September of 1974 and at that time there were twenty-five people on staff. There were three people that were full time: there were myself, and I was hired initially as the receptionist, James Jackson, who was sort of a co-receptionist, and Norman Anderson, who was the driver of the microbus. CIL had a Volkswagen microbus and he provided transportation services. And I was just thinking about the early days, the people who were there and how everybody really enjoyed being there and liked who they were working with and what they were doing. I just think some people deserve mentioning and so I'll just sort of go down the list, which is:

Ed Roberts was the director at that time and Joan Leon was his administrative assistant, who was really brought on to do a lot of fund raising and grant writing. Then there was Phil Draper who was the assistant director. And in services, Greg Sanders was doing advocacy, Cathy Caulfield and Don Berry were doing attendant referral, Lynn Kidder was doing Medi-Cal billing for wheelchair repair, and Gary Rowan was doing wheelchair repair. Camille Plunket was the secretary of the board and she used to do the minutes and work with Phil, who in addition to being the assistant director was also the president of the board at that time. Bill MacGregor was the bookkeeper. He had volunteered for that mission, and worked really hard at it. Ruth Grimes was doing some statistical work; she was there not a whole lot but she was one of the very early people who contributed a lot to the formation of CIL. Jan McEwen was the editor of The Independent and Ken Okuno took all of the photographs for The Independent. Don Galloway was the head of Blind Services which consisted of him and Carol Wiebe, at that time, who was doing orientation and mobility and who was with CIL for years and years, in that capacity. And then there was Kitty Cone and Hale Zukas who were doing--I was trying to think of what it was called--and it was Community something--

O'Hara: Community Affairs, wasn't it?

Lester: Community Affairs, right. Kitty was the one who was responsible for getting people organized around saving attendant care every year--seemed like we all had to go to Sacramento and do a big

thing to try and save it year, after year, after year; it was always under the axe.

O'Hara: The whole staff went?

Lester: A lot of people went. Well, there was the 501(c)(4) called Disabled and Blind Action Committee of Northern California; it was that arm that did the organizing of the demonstrations and stuff. Not everybody went, they got a lot of people in the community to go.

Hale Zukas, of course, was out there watching every single curb cut that was being put in the City of Berkeley and telling them where they should be putting it. [laugh] Hale just deserves a tremendous--both Hale and Kitty deserve tremendous credit for everything that happened at CIL and in the environs. They were just absolutely critical to what was going on. And then there was Peter Leech and a woman named Jeanne InDelicato who was working with Peter. They were doing that training project that we talked about before, where people would come and live--taking on the role of a disability for a week. They were the ones that were doing that. And Nancy D'Angelo was on staff then; she was sort of Ed's secretary and later was doing attendant referral. And Janice Krones was on staff as the dispatcher of the microbus and Norman Anderson. [laughter] And I think I'm missing one, but--

O'Hara: Very good!

Lester: Yes, it's pretty amazing.

O'Hara: So that was the number in 1974 and you said by '76--

Lester: Yes, according to the Affirmative Action Program we wrote for the City of Berkeley in February 1976, there were eighty-eight people on staff.

O'Hara: So you're quoting the Affirmative Action Policy in the archives?

Lester: Absolutely. It's a fascinating document. And it does--it bears out what we thought last time, which was that basically it was about half female, half male. This shows that there were 55 percent male, 45 percent female, and 49 percent people with disabilities. One thing that I've heard tell is getting lost in a lot of independent living centers--the emphasis on hiring people with disabilities--and in fact, that leads me to a couple of points I wanted to make:

This sort of rapid growth was precipitous in these times--as I mentioned, Ed was lobbying very heavily in Sacramento for his

job, and the organization was mushrooming right at this time. Ed was doing a lot of hiring. People wanted more information about what was going on, and why: what was the direction for the organization, what was the plan, how people were being paid? They saw a lot of people coming in the door, but there wasn't a lot of information about new grants or resources to cover them. And we were growing so fast, things were changing so quickly, and there seemed like there was a lot less information forthcoming, so there was a growing rumbling.

O'Hara: And when was this?

Lester: This would have been probably the summer of '75 because we moved to Telegraph Avenue the weekend of the fourth of July of that year and Ed left the end of October.

O'Hara: For Sacramento?

Lester: For Sacramento, right. And so it was somewhere between July and November and probably around the end of August or September and it was decided that we would hold a retreat where the whole staff would gather for two days and talk about these issues. Lynn Kidder was very instrumental in organizing it, and a lot of other people--I think Kitty probably got involved. It was like so many other things. We were flying by the seat of our pants, but it was decided that this was what we needed to do--have this big communication session where we could ask questions of the people who were making decisions. We would get answers and everybody would have regained a feeling of ownership. And what happened was Ed decided to bring in a guy named George Pransky, who is this therapist, and he came in basically to turn the whole thing into a touchy-feely session and diffuse all of the issues without dealing with any of the questions and it was--[sigh] I think it was sort of effective for the people who wanted to diffuse the situation, but it left a lot of people feeling more frustrated than they had felt before.

O'Hara: What was the general reaction?

Lester: Well, I can really only address the first day, because at the end of the first day, I wound up with a roaring case of the flu and did not attend the second day, which was culminated by a big party. I think everybody loved the big party--as I mentioned before, we had a lot of parties and people loved our parties. They really did bring people together and made them feel part of the family and part of a very unique organization, for a lot of different reasons. I think people, for a long time, talked about how great that party was. Apparently at one point, Ed had this very long push broom that at the end of the day he was pushing

around. We were in this lodge that was operated by the Oakland Parks and Rec Department--it was a big open room and he was sweeping it, going up and back and forth with this push broom that he was pushing with his chair. And you know, I think people felt very good about that, they felt that everybody had rolled up their sleeves, but there was still all of these unanswered questions. So I think it served a purpose, it served one purpose as opposed to another purpose, and what a lot of us had originally felt was the intent.

O'Hara: Well, what happened to the questions and the issues after this retreat?

Lester: Well, basically, the questions resurfaced after Ed went to Sacramento. Phil and I had a number of meetings with Joan and Ed about these kinds of issues--in the passing of the torch with Phil taking over, we were trying to get very clear about what fund was covering whom. It really wasn't until after Ed left that we began to really sort it out, and that's when we became very aware of the extent to which we were running a deficit.

O'Hara: Oh, really.

Lester: Yes, it started emerging, I think, in the early months of '76.

Role of Nondisabled People

O'Hara: Is this the same time as--you said that you had some more to say about--was it tension between disabled and nondisabled?

Lester: Yes, and what I wanted to say about that was that in any civil rights movement--in a civil rights movement you're going to have outsiders, and in this case the outsiders were people without disabilities. And because it was a civil rights movement, I felt the people coming into it were aware of that and bought into it and were committed to it to a large degree. But the problem, then, was that--being an outsider in a civil rights movement is not an easy thing to do, and a lot of it created a lot of tension. For example, there were a number of people, myself included, who were in a position of a lot of responsibility but theoretically no authority, and it was a tough place to be.

O'Hara: How did that work? Can you cite a specific example?

Lester: Had I had a disability, in all likelihood, my role would have been more of an assistant director than assistant to the director.

Judy was very much the deputy director--and I'm not saying that I was playing on that level at all, but that I had a lot of managerial responsibility and had I had a disability, I would have been the assistant director, most likely. I also would have had more of a visible stake in the organization; I would have been seen more of a spokesperson. But it's the nature of the conflict of being an outsider in a civil rights movement and I chose to be there, and I wanted to be there, and I believed in it wholeheartedly. One of the main reasons CIL was so successful was because of its commitment to hiring people with disabilities. I also think we failed a lot of people with disabilities by not giving them appropriate training and it was set up for them.

O'Hara: As employees?

Lester: Yes, and it created a lot of problems in the organization.

Lack of Training; Noncollaboration; Antiprofessional

O'Hara: What kind of problems?

Lester: Well, people not having the skills that they needed to do the jobs that we had set out for them to do. So it meant that we were creating situations for ourselves that we just had to deal with constantly. But like I said, earlier, too, we were all OJT's--we were all on-the-job-trainees--we were all learning as we went along. I think a lot of it--we've talked about this a little bit before, too, was that the training opportunities and educational opportunities that people with disabilities had up to that point were very limited. A lot of people, as we all know, were in school and getting more physical therapy than they were getting science, math, and English.

O'Hara: Were there other people on the staff and in your situation that, where you feel if they had had a disability, they would have had a higher classification in the organization?

Lester: I think so. A number of people fall into that category. I think Bette McMuldren and Lynn, had they wanted it. I mean they were doing roles that were more than just what the title said. Of course, in part, too, that was because we didn't have a whole lot of people, we didn't have enough people--certainly not in the administration--because the infrastructure didn't grow fast enough to keep up with all the projects. And in part that again gets back to the problem of funding and that funding doesn't cover all the administrative stuff it needs to. But I think, yes, there are

a number of people who would have had different roles and seen themselves very differently in the organization. But, there again, they too were there because they really believed in it and they really believed in the fact that they were involved in a civil rights movement, and that's just the dilemma.

One of the other things that I think other organizations have dealt with that CIL didn't, for a lot of reasons, was CIL was not a very collaborative organization. It started as a reaction to Rehab, a reaction to the adult service-providing world and it was very antiprofessional. It did not welcome professionals as members or as staff people because it was those professionals that everybody was gathering to react against to create a better organization.

O'Hara: You mean as professionals--trained rehabilitation counselors, or--

Lester: Right, occupational therapists, physical therapists, and the whole medical rehab world.

O'Hara: When you say that CIL was formed in reaction to professionals, can you elaborate on that a little bit?

Lester: Well, the expressed view was that people were tired of being told what they needed and what they should have. They felt very much that they knew best and that they could do a better job of delivering it than the people that had been doing it for so long, because needs weren't being met. And people didn't feel that their needs were understood by professionals and that was the whole reason that CIL came to be--not to mention the fact that there were certain services that weren't being provided at all. You know there really was no place that you could get wheelchair repair (unless you were a student at UC), there was no place you could get an attendant referred to you. So in addition to feeling that the traditional service model wasn't doing a good enough job of what they had set out to do, there were all these other things that they weren't even trying to do. Things that weren't being done by anybody, and that was the whole business of determining what the needs were and knowing how to fill them.

O'Hara: And this feeling, then, against "professionalism," (in quotes) are you saying that that led to hiring people who were members of a minority group but not necessarily qualified?

Lester: Well, I wouldn't say not necessarily qualified, because there were some very creative, very committed people. We were all kind of figuring it out, and some people needed more training and guidance than others. A lot of people did just figure it out on their own, but some didn't. I think we failed some people a lot--not

everybody, it's not across the board, but we took on a lot of OJT's--on-the-job-trainees. I think we could have done a better job at training a lot of people who took those jobs. And again, it was not because we didn't want to--it was just the lack of resources to do it, in some cases.

O'Hara: You said that CIL is not very collaborative, what did you mean?

Lester: Well, instead of embracing other groups--like embracing parents, for example, and embracing all disabilities, and embracing professionals, they didn't. They very much separated themselves from pretty much everybody else. And I think it was a necessary thing to do, but at a certain point I think they would have been better served by reaching out--as Judy did. I think Judy was probably one of the few people that had that philosophy and that vision about the fact that it needed to be a more inclusive group than it was. Parents, for example, were not welcome at CIL and I think historically the parent movement in this country and the independent living movement in this country has been very separated and there hasn't been a lot of mixing.

O'Hara: What do you mean by parent movement?

Lester: I mean all of the parent support organizations--parents of children with disabilities. I think there could have been some really fertile collaborations going on there that typically haven't and I think there are some good reasons for it. I think some organizations are better at building those bridges and reaching out than others. CIL in the early days was very distant, was really distancing and separating itself from all of that--for good reasons--I mean, it was about building their own strengths, and direction, and vision.

O'Hara: Was CIL influenced by other civil rights movements that were going on at the time?

Lester: Oh, I think very heavily. Certainly the black civil rights movement had a major impact, I think, because in many ways it was the same struggle and I think everybody who was involved was very aware of that. Also, as we said before, all of these people for the most part were very left or liberal--some left, but all very liberal politically and very aware of others' struggles. And a lot of people learned--I think Phil, and Judy, and Ed were very aware--it had a strong impact on the leadership of the organization.

O'Hara: When you say the same struggle, what do you mean--you were referring to the black civil rights and the disability rights?

Lester: Yes, well, in many ways it's the same; in a lot of other ways it's not the same. It's interesting--to digress a little bit--I'm working on a diversity committee for the Support Center, a nonprofit management consulting firm for nonprofits. There's a young woman on that committee and we were talking about discrimination. She was suggesting that they needed to target people from minorities because they had experienced the most significant discrimination over the years. And I said, "Well, you know, it depends on how you define most significant discrimination, because you know the unemployment rate among adults with disabilities is over 66 percent, which I think you'd be hard pressed to compare to most other groups." And she was stunned and amazed. But I think there are some parallels that can be drawn in terms of economics and discrimination. It's about lack of access to resources--to jobs and training--to housing--to adequate health care.

O'Hara: In jobs?

Lester: Yes, in jobs, and housing, and transportation. I mean, there are a lot of similar issues--it's about people not wanting to think about people other than themselves. [laughs] Well, that's a little strong.

O'Hara: Tell me about the CIL in Oakland, which I think you said consisted of Black Panthers?

Lester: Yes, well, Ed made a connection with the Black Panther party in Oakland. This was in the mid-seventies, so a lot of the Panther activity, certainly the heavy military activity, had really died down and they were doing a lot of work in East Oakland with food programs, education programs, and health programs. And Ed made a connection with--I'm not sure who, but with the Black Panthers and opened a satellite office in East Oakland. Arlene Clarke and Brad Lomax, who was a guy in his early twenties with a disability--an African American who was part of the Panther party--and it didn't last real long. I think maybe it went on for about a year, if that. And I think the goal had been to provide attendant referral and some of the basic core services to the community out in East Oakland.

O'Hara: So that's an example of a type of coalition?

Lester: Yes, it is. And it's a good example in many ways. It wasn't a highly successful one, for a whole variety of reasons. I think there are other coalitions that might have been more successful. That was a leap for that group.

O'Hara: For CIL?

Lester: Yes. It was a big leap.

O'Hara: Were there other coalitions that you can think of?

Lester: Not in those years.

O'Hara: You mentioned before support from the university. I suppose you could call that a form of coalition?

Lester: Yes, and that's another good example. That was a good collaboration that was very, very beneficial for CIL. And I know there were some others and they're just not coming to mind.

O'Hara: Well, we might think of them later. Well, that finishes that tape.

Lester: Really!

Perception as Symbol

O'Hara: The term--CIL became very famous and their name is very famous, it obviously symbolizes something with all its flaws. [laughter] What does it symbolize? Why has it been so powerful? Or has it?

Lester: Well, I think it was. I think it was very powerful and it's a very interesting question why. I think one of the reasons is because it had some very high-profile people associated with it who later went on to get even higher profiles. And a lot of people did scatter--a huge number of people involved with it went off to do other things, taking parts of CIL with them. We were also very experimental--both Ed and Phil were willing to try all kinds of things, as was Judy, who you know, accepted all sorts of odd projects to take on that they thought were innovative or would have some value. CIL was in many ways an incubator for projects: somebody would come in the door, as we discussed earlier, and say, "I have this project," and we'd say, "Okay, write a grant and if you get funded, we'll run it." Then a lot of them spun off.

There were just a lot of creative people--like the Computer Training Project, for example, which is now the Computer Technologies Project. Scott Luebking and Neil Jacobson basically came in with Rehab and IBM with this idea and started an organization, which was highly successful and spun off. In fact has been a model for a whole network of organizations like that all over the country. There's a whole--I forget what the name of it is, but there's an organization of computer training projects.

And then there is DREDF [Disability Rights Education and Defense Fund], which was started as the Disabled People's Legal Resource Center and also spun off. First it was DPLRC--shortened soon to DLRC.

But CIL attracted a lot of the best and the brightest who had a lot of creative ideas. And it was a place that they could try them out. Judy's had a lot to do with why CIL became so famous, and the fact that Ed went to Sacramento raised the profile of CIL dramatically. Also California was probably one of the first--and you'll have to correct me on this, because I wasn't really involved in this, but I think they were probably one of the first states to legislate funding for independent living centers. And Ed had a tremendous amount to do with that in Sacramento.

And also, Berkeley attracts attention just by the nature of it and with the Free Speech Movement being here in the early sixties. That had an impact on just about everything that followed afterwards because all eyes turned to Berkeley. And I think, "Ah, hotbed." I think things that are done here are magnified in ways that they might not be if they were done elsewhere.

O'Hara: What was it that was drawing these people that you've talked about from all over the country and even beyond?

Lester: Well, as I mentioned, we would get dozens of letters every week from people wanting to know more about what we were doing and wanting to come to Berkeley because they'd heard about the university. The university was a big magnet, too, because of the disabled student services. And the Cal program brought a lot of people here that later became involved with CIL. And people would say, "What are the benefit packages like? What's IHSS [In-Home Support Services] in California? How much is SSI [Supplemental Security Income]? How does Medi-Cal work, and is there housing?" We would just get letters like that all the time--and I don't know how they were hearing about us.

O'Hara: But there was something about the idea that people jumped on?

Lester: Yes. There was something about the idea, and people heard about it. And like I said before, part of it was the climate, both politically and just environmentally it's so much easier than in other places. It's a more accepting climate and it's just a much less harsh physical environment than a lot of places like New York and Chicago, where a lot of people came from, and wound up in Berkeley.

Phil Draper's Wedding

O'Hara: Was Phil married, or did he get married while you were at CIL?

Lester: Oh yes!

O'Hara: Can you describe that?

Lester: Well, it was an interesting thing. It was one of the big events of the CIL world. As I mentioned, you know, one of the major roles CIL fulfilled for people was the social one. The social aspects of CIL were very important to the community and really made it a community in a lot of ways. It was a place where people could come and hang out and just be people, and be around people who made them feel comfortable and accepted. Betty Medsger did a series--she was a photographer who had gotten connected with CIL. I don't remember exactly how she got connected, but she wandered in one day and made a very strong connection with Lynn Kidder. Betty was doing some photographs about people with disabilities and she--I bring her up because she identified Phil's wedding as an important event to photograph. There were actually a lot of weddings that happened in those years, that were great fun. And Phil's happened in 1977--I think that was the year. The entire organization was invited, there must have been 300 people. And it was a large, Catholic wedding.

O'Hara: Who did he marry?

Lester: He married Sharon Amato, who took Phil's name and was Sharon Draper, still is Sharon Draper. They had been living together for many years, about seven or eight at the time.

O'Hara: Did he meet her at CIL?

Lester: I don't think so. But that's an interesting question. I don't remember where Phil and Sharon met. But Sharon was born and raised in Berkeley and her father was a commercial fisherman. And in planning the wedding, Lynn Kidder and I got very involved in it, and it turned out to be quite an event.

O'Hara: You were both members of the wedding party, weren't you?

Lester: We were, which was, for us--let me put it this way. We were not in the habit of wearing dresses and sandals and hats and so it was a very large commitment from us. And everybody sort of turned--for these events everybody would, you know, try and look their best and dress up. It was a scruffy bunch of people at best--they were hippies who hadn't even tried to transition out of the

sixties at that point. I think everybody made more of an effort in the early eighties, after Ronald Reagan was elected [laughter] but at the time in the seventies, people were still just not into the dress and suit scene. So this was--everybody, yes, got dressed up.

And unfortunately, I missed one of the most talked about events of that wedding, which was a dance. There was dancing in the basement of the church and Sharon was wearing a very large, white wedding dress and Lynette Taylor was all dressed in black because she was the interpreter for the deaf. My understanding is that they started doing this dance; Phil was in the middle of the room and Sharon and Phil were dancing, and Lynette started to horn in. Then Sharon and Lynette, got into this vamp/virgin dance around Phil that I'm told was absolutely extraordinary.

O'Hara: Is that on film, at all?

Lester: You know, I don't think so. This was sort of before the home camcorder. But everybody was just--everybody totally got into it, and it was really [laughs] quite the thing.

O'Hara: Was it unusual for a person with a disability, a wheelchair user, to get married?

Lester: No. At that time--well, I think in the outside world it might have been, but not in the Berkeley world. I remember a whole rash of weddings having taken place in those years: Judy Taylor got married--didn't she have a wedding up at UC? Don Berry and Carol got married on campus. Phil and Sharon--Ed had gotten married: Ed and Cathy had gotten married--boy, I can't even remember when that was. I think that must have been--that may have been after they went to Sacramento.

O'Hara: Yes. '76, maybe.

Lester: Yes. So it was still out of the mainstream but it was pretty common in the CIL world at that point.

O'Hara: What made you eventually leave CIL [in 1981]?

Lester: Well, there were a lot of things. You know, the finances were not good and at a certain point we began to lay people off, things got tight and grants were running out. And because we had been juggling so many grants for so long there were--that's actually one of the problems that you get into when you're juggling that many grants: you try to hold onto everybody and it's hard, you can't always. Grants are time-limited and project-specific and it gets very difficult after a while. It was one of the problems we

ran into with the union and wanting seniority in a situation that just couldn't support it at all because the money was so soft.

O'Hara: Yes.

IV AFTER CIL

Disabled Children's Computer Group

O'Hara: And you went to work for a couple of organizations that were not disability related. You got out of the business?

Lester: I did, I did. Not specifically on purpose, just because that's sort of where things led me for a while. I got back into it when Judi Rogers, who had been on staff at CIL called me up and said, "You've got to meet Jackie Brand; she's doing a project with kids and computers, and you've really got to talk to her." And so Jackie and I connected and at the time, she was the coordinator for the Disabled Children's Computer Group which was a very small organization trying to provide access to technology for people with disabilities. She had a donated classroom in the Richmond Unified School District to use as a resource center. She shlepped her daughter's Apple II Plus from home to school and back again everyday, so that when her daughter was in school, Jackie would have the computer to work with, instructing teachers and parents in how to use software. She would also have adaptive devices, which at that time were few and far between, to provide access to technology for people who couldn't use a regular keyboard.

O'Hara: Was she working with them so they could in turn communicate with her daughter, or what was her purpose exactly?

Lester: Her husband Steve, in 1983 had taken a leave of absence--he was a teacher and had felt that computers should be able to help their daughter and he needed to figure out how. And it was 1983 when the PC was basically brand new. The Macintosh had just been released with a 128K memory. And so he took some classes and he met a guy named Steve Gensler who in his basement had put together--he was an engineer trying to design a communication board for a friend of his named Frank Moore. Seriously. And he gave the board to Steve Brand and said something like, "You're

going to need a computer interface card for this--and if you ever get it to work, let me know."

So Steve did get it to work--it was a huge board that was probably about three feet by a foot and one half and it looked like a giant, painted circuit board. And they programmed half of it so that when their daughter, Shoshana--who now goes by the name of Judith--touched it, on the left side it would go one color--blue, I believe--and if she touched it on the right side it would go red. It didn't require very much touch and it didn't require a lot of vision and it was the first time that she could control anything in her environment. She at that time was about eight years old. Then the next step was they programmed it in four quadrants, and it was a letter to her grandmother. It went something like, "Dear Grandmother, I love you very much, quit smoking, love Shoshana." Shoshana cranked out dozens of these letters and sent them to her grandmother. [laughter]

O'Hara: The same letter?

Lester: The same letter. [laughter] And there was a very rudimentary talking word processor called KeyTalk that had been developed, I believe, down at UCLA. So they had put this system together because Judith up until that point, had been sitting in the back of the classroom fully mainstreamed, but not able to use any of the tools. She couldn't turn the pages of a book, she couldn't see the blackboard or hold a pencil--basically had no access to her education until they put together this computer system. And in doing that, they realized that they had the skills and the resources to do that because of who they knew and the fact that they were in the Bay Area which was pretty rich in resources. So the Brands decided to start bringing together groups of people who were interested in maybe putting something together so that people who didn't have that access could benefit from this knowledge and people wouldn't have to reinvent the wheel. So that's how it all got started.

And then Steve Gensler went on to develop what they then called the Unicorn Board. And now it's evolved into a keyboard called IntelliKeys. It's a very successful company, IntelliTools, and it's now over in Novato, but it's one of the main assistive technology companies in the business and doing very well.

Alliance for Technology Access

O'Hara: Was there any relationship in concept between the Disabled Children's Computer Group and CIL? I mean, was this all part independent living?

Lester: In many ways it is, and in fact, the Disabled Children's Computer Group became a model for centers around the country and we developed this network called The Alliance For Technology Access [ATA]. A number of our centers are located in independent living centers. We feel that technology is a very important part of everything, and every independent living center, to our way of thinking, should be providing technology services. In fact, every organization, we believe, that works with people with disabilities should be looking at technology as a service and also as a tool to provide services in terms of the organization. One of the things that we did early on at ATA--that CIL didn't--was to really push this notion of collaboration. It's sort of a different focus--I mean, by being focused on technology and starting as a small group of parents with an education focus, initially, it made total sense that you had to get the whole team involved to really make it work. If you were going to give kids tools to work in a classroom, then you had to have buy-in from all of that support network.

O'Hara: The schools?

Lester: The schools, the teachers, the OT's [occupational therapists] working in schools--and their participation was critical. Also you needed a lot of expertise from the technology world, and so from the very beginning we were a collaboration of professionals, parents, and consumers--adults with disabilities, and technology developers.

O'Hara: What was your role in these two organizations? What was and what is?

Lester: Well, I came on board at DCCG to raise funds, to write grants, primarily. But when I came on board, it was just Jackie--and then me.

O'Hara: Oh.

Lester: Yes. So there were the two of us. We had a very strong and wonderful board of directors that was really a working board: I mean, they had an open house committee that took care of the open house, they had a newsletter committee that wrote the newsletter, and a lot of them volunteered as staff. My role was to develop resources, and then I evolved into the associate director in charge of operations, basically. When the Alliance started, which is a national network, I started working part-time for them, so I

was working for both organizations for a while, and then I shifted over.

O'Hara: I see. And then what role are you taking in the Alliance?

Lester: Well, I'm basically associate director of operations. I do a lot of grant writing, and program development, and I do a lot of the budgeting and finance work. In many, many ways the same kind of stuff I was doing with CIL all those years ago. Now I'm doing more program directing.

O'Hara: What is the link between the Alliance and the other technology access centers?

Lester: All of our technology centers are independent 501(c)(3)'s, so they're all either umbrellaed by other 501(c)(3)'s in their community or they're independent organizations and they all belong to the Alliance. So the network is called the Alliance and our office is the national office of the Alliance. And what we do is provide training and technical assistance and some equipment. We write grants for projects that involve groups of centers, and we do some demonstration projects, and we do some advocacy work. We've gotten a grant to do some advocacy, some technology policy work, in rural communities coming up here in the next few months that we're really excited about--that's being funded by Kellogg. So that's, you know, the kind of stuff we do.

And we wrote the book, Computer Resources for People with Disabilities. We actually--our office edited. We got all the centers involved in doing the technical contributing and writing--I got to be the editor on that. And it was a phenomenal experience; we wrote the whole book on-line. We were one of the very early pioneers of uses of telecommunications. Apple, when they helped get us started, gave us free use of AppleLink (Apple's proprietary telecommunications network), starting in 1986. And we built a nationwide network using telecommunications to do it very early on in the technology revolution. And we did a good job of it.

O'Hara: Good. Congratulations.

Lester: Thanks.

O'Hara: Well, what have we forgotten? What do we need to add?

Lester: Whoa, I don't know. I guess that's sort of a good note to end on. I mean, a lot of people from CIL spun off to do a lot of very interesting stuff and I'd be real interested to know where a lot of people have gone to and things they have gone on to do.

O'Hara: I would imagine that CIL--that their work at CIL and their life at CIL had an impact on whatever they did in the future.

Lester: Yes, I think it did. I think a lot of people look back. I mean, I would hope that people look back on those years as very formative ones. I certainly felt like it was worth ten graduate degrees, for sure. Yes, it was very formative. Well, and you know, as I mentioned, too, a lot of the people who were there were in their twenties and early thirties and it's a very formative time. I would like to think that people got some good insight into the human spirit and went off to do inspired and wise things with it. [laughter]

O'Hara: [laughter] Well, thank you. And it's a wonderful, wonderful place to end.

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Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME I

Bette McMuldren

ASSISTANT TO JUDY HEUMANN AND GRANT WRITER
AT THE CENTER FOR INDEPENDENT LIVING, 1975-1980

An Interview Conducted by
Sharon Bonney
in
1998



Bette McMuldren, August 1998.

TABLE OF CONTENTS--Bette McMuldren

INTERVIEW HISTORY	121
BIOGRAPHICAL INFORMATION	122
Early Years: Education, Urban Renewal Work, Master's in Rehabilitation Counseling from New York University, 1948-1975	123
Arrival in Berkeley, Meeting Ed Roberts, Volunteering at CIL, 1975	126
Judy Heumann's Assistant and Grant Writer for CIL, 1976-1978	129
Judy Heumann's Internal Role at CIL and Her Work Style	137
Judy Heumann's Goals and Vision for CIL and Her 504 Sit-In Activities	142
Department of Rehabilitation and Its Relationship with Judy Heumann	148
Judy Heumann's Affirmative Action Stance	151
Coalition Building and Disability Hierarchy	152
Judy Heumann's Interactions with the Media	156
Disability as a Civil Right	158
Impetus for the Movement in Berkeley	160
Michael Winter as an Intern at CIL	162
Leaving CIL and Work in Santa Barbara and Arizona, 1980	163
Final Thoughts	167

INTERVIEW HISTORY--Bette McMuldren

In the mid-1970s, the Center for Independent Living gained national recognition and experienced a tremendous growth and expansion in services, programs, and staff. Bette McMuldren, a non-disabled woman, volunteered at the center in 1975 and soon found herself swept up in the hectic pace of working in a developing grass-roots organization. Her interview discusses her role as assistant to CIL Deputy Director Judy Heumann and her observations of Ms. Heumann as a leader; the organizational culture of CIL and the people who worked there; and the awe and support of the outside world towards the center and its activities.

Ms. McMuldren describes her inability to manage the paper generated by Judy Heumann, the hectic need for follow-up with hundreds of people Judy met while traveling, and the constant flow of visitors who had heard of the center and wanted to tour it for themselves. She observed Judy Heumann in the role of CIL marketer, in her day-to-day running of CIL, and in her relationship with the media. She illustrates Judy Heumann's highly developed persuasive skills, her political acumen, and her role in the Section 504 sit-in in San Francisco in 1977.

Her oral history offers an internal look at CIL and the people who worked there. CIL was a mixture of people with disabilities and without disabilities; of communists and socialists; gays and lesbians. Judy Heumann promoted total inclusion of people with disabilities in all aspects of life, affirmative action, and people in non-traditional roles. Bette McMuldren describes a perceived hierarchy of people with disabilities and talks about the differences, as she saw it, between people born with disabilities and those who received them later in life. In one of the most moving segments, she tearfully talks about the importance of CIL to people with disabilities who arrived with no hope for a meaningful future. The transformation from hopeless to fulfilled people was a miracle she saw several times.

In addition to her work as Judy Heumann's assistant, Bette McMuldren helped develop the grants and contracts office. She observes that organizations were eager to fund CIL if they could come up with a program idea, but were unwilling to fund the day-to-day operations and that is where the financial squeeze developed. The growth of CIL during this time period was due in large part to the success of Bette McMuldren and the other grant writers.

One interview session was conducted in Ms. McMuldren's home in Tucson, Arizona, on October 8, 1998. Interview topics had been sent prior to the meeting and several information exchanges over the Internet took place before the interview occurred. The interview was held in the dining room overlooking a lush garden. During the interview there were several tape interruptions when her two cats came to visit. One cat had just gone

through cancer surgery and chemotherapy and came out of his room for the first time during the interview, much to Bette's delight. Bette graciously baked quiche for lunch for the interviewer and her husband and said it reminded her of the early days at CIL when she made many quiches for potlucks.

The transcript was lightly edited by the interviewer, and Bette McMuldren made minor corrections and added information in places. During final proofing, the interviewer made additional minor editing changes. Bette donated a number of pictures for the archives as part of this project.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sharon Bonney
Interviewer-Editor

June 3, 1999
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

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Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Bette K McMuldren

Date of birth 12/3/48 Birthplace Akron, Ohio

Father's full name James McMuldren

Occupation shopkeeper Birthplace ~~Akron~~ Patton, PA

Mother's full name Leona Vines McMuldren

Occupation teacher Birthplace Osgood, Indiana

Your spouse Skip Bingham

Occupation manager Birthplace Phoenix, AZ

Your children None

Where did you grow up? Ohio

Present community Tucson, AZ

Education Muskingum College - BA

New York University - MA

Occupation(s) Rehab Counselor, Training Director

Areas of expertise training

Other interests or activities rafting, hiking, exercise

Organizations in which you are active _____

INTERVIEW WITH BETTE MCMULDREN

Early Years: Education, Urban Renewal Work, Master's in
Rehabilitation Counseling From New York University, 1948-1975[Date of Interview: October 8, 1998] ##¹

Bonney: Bette, let's start out with background and early history. Tell me a little bit about where you were born and your parents and your family.

McMuldren: I was born in Akron, Ohio, in 1948. I'm going to be fifty this year. I have one sister. My parents were older. My mom had been a schoolteacher. Basically, she was kind of an old-maid schoolteacher when she got married, in her mid-thirties, so I was born when she was in her forties, as was my sister. Anyway, we lived in Akron, Ohio, and my dad worked for the railroad. My mom was a teacher.

Bonney: What were their names?

McMuldren: James and Leona.

Bonney: What?

McMuldren: McMuldren. Yes, I kept my name. Gosh, what else should I tell you? Then I guess--uneventful. I graduated high school in Akron, and then I went to school in a small college in southern Ohio, Muskingum [College], which was a pretty conservative, Presbyterian school, fourteen hundred students. So my background was really very conservative. You know, went to church; my parents stayed married; everything was pretty much middle America. You know, white bread, potatoes and meat kind of diet. Everything was pretty conservative. My folks were definitely conservative. I mean, not reactionary or anything, but just pretty middle-America type.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Anyway, so I went to school at Muskingum, and then when I got out of school I moved to Washington, D.C., with one of my girlfriends. Actually, what happened was my dad died when I was in college, so my mom was by herself. There was a big tug to stay with her, so really I think my emancipation was to get out and move away to Washington, and I went to Washington, D.C., with this friend.

Lived there for--I want to say three--I think three years. What I did there was a social work job with the urban renewal agency [District of Columbia Redevelopment Land Agency]. I worked within the inner city of D.C. with families that needed to move because they were living in substandard housing. Most of it was overcrowded situations. My clients were mostly single, head of households with nine kids and rats and just, like, awful.

The job was I would go into these buildings, and a lot of times people were--they were maybe the last family in the building--so I would go into these empty buildings with, like, drunks and all [chuckling] this stuff. I think back on it now, and I just think so much that I was, like, protected. I mean, I hardly believe the environments I was in, really.

[tape interruption]

McMuldren: One of the things that happened was that I worked with these families, and what I began to realize, especially with the single women, was that the only thing that really helped was getting them jobs and getting them job training. Because the job, itself, was to find them other housing, but the problem was they couldn't afford any housing because they were all on welfare and they had no skills. The job became this interest in people who were inner-city, disenfranchised and trying to connect them with job-training programs. I did a lot of that, like referrals and talking with some of the women that I worked with about getting into training.

Then I had a friend that was also a counselor with me there, who had left. She had moved to San Francisco, and she had gone to school to be a rehab counselor. We were in touch. Anyway, it was a combination of this experience of finding that job training really helped people and my friend telling me about her program at UC San Francisco--University of San Francisco. That's what it is, right.

It was just time to do something else. I needed to go to graduate school. So I applied to graduate school. I applied in social work and in rehab counseling. By this time, I had

gotten involved with my husband. He had dropped out of school. He was being a hippie actor. He had decided he was going to go back to school and finish his degree. I had applied to graduate schools, and I was going to go to either Kent [State University] and go back home to Ohio, or I had George Washington University or NYU [New York University].

He was from New Jersey. He wanted to go back to New York, so we decided to move together back to New York. I went to graduate school; he went to undergraduate. Finished at Rutgers [University]. Anyway, so I went to this program at NYU in rehab counseling. I lived in New York for two years and studied rehab counseling. In the seventies, that was '73-'74 and '74-'75 were the years I was in that program. I went from this social model of helping people in the inner city--and then the rehab program was, like, oh, wow, social disadvantage is not [chuckling] disability. So I really didn't have any real exposure to disability or any particular knowledge of that when I went to the program. I really came from this other direction into that rehab counseling program.

When I got in the program, faculty had disabilities, lots of the students in the program had disabilities. I went to graduate school with a woman who was in that group of folks that had all gone to school together, in grade school in New York, which was Judy [Heumann] and Steve Hofmann and Neil Jacobson and Nancy--what was her name? Nancy [D'Angelo]. Anyway, they had all grown up together; they had all gone to public school together. So later I learned that one of my peers in graduate school was from Judy's early group of school friends.

The program was a pretty clinical model. I don't know, really, if it still is; but it wasn't sort of rehab counseling in the sense of vocational counseling. It was more clinical counseling: psychotherapy or whatever. I did these internships while I was in the program. I did one in a psychiatric program, which was a horrible experience for me. Then my second year I did my internship at ICD.

Bonney: Which is?

McMuldren: It's a pretty big program in New York. The original name of it stood for the Institute for the Crippled and Disabled. There were a number programs, right? There was a workshop, I think. The program I was in was a speech program for people who had had laryngectomies.

[tape interruption]

McMuldren: Well, the thing that's kind of interesting is that I have contact with them now, and they're called the International Center for the Disabled [chuckling], so they're still called ICD [chuckling], but at least they have moved a little bit in their orientation [laughing]. At the time I was there, they called it just ICD. The acronym meant nothing. So they have evolved.

So I worked in this program for laryngectomies. I did individual counseling and group counseling with people who had had cancer, and learned, I think, really good counseling skills because the woman that supervised me was really good. She was, like, just the best. Also, while I was there, I worked with these people at the Rusk Institute. Two of the women who were the rehab counselors from the Rusk Institute also worked with us over at ICD. They were in and out of our program.

I think the NYU program gave a lot of medical information. You spent time at Rusk Institute. It was real kind of clinical. You know, teaching how to counsel and stuff.

My second year, I was still living with my husband. We decided we were going to get married. He was going to go to graduate school because he had finished his undergraduate and he was working at Cornell Medical Center. He applied to graduate schools. His dream had been to go to Berkeley. So sure enough, he got in. His field was totally unrelated to rehab or disability. He was a biochemist. But he got into Berkeley, and so we went across country. We stopped in Ohio. We had a wedding. Then we drove cross country. It was really fun. That was a fun summer.

So we got to Berkeley.

Arrival in Berkeley, Meeting Ed Roberts, Volunteering at CIL, 1975

Bonney: So now it's the summer of?

McMuldren: Summer of '75. I want to say--no. Yes, '75. It was August, September we got there. I started looking for a job, and he started school. What I found was this whole movement. Basically, oh, you're in a field that works with people with disabilities. There are no jobs for you [chuckling]. You're not disabled. Sorry. You're not welcome. It was very tough. It went for several months that I looked for jobs.

The thing was there would be these jobs that would be in these very traditional places, like Goodwill or I remember there was some program in Oakland, in the hills, some kind of workshop. I kind of looked at these sheltered workshops. It was really pretty dismal. Just really didn't know what I was going to do. It really wasn't what I wanted because my training really had been in counseling. So I think had things not gone the way they went, had I stayed in New York, I probably would have become a therapist or something because that was really the bent of my training.

Instead, what happened was I ended up in Berkeley. We lived right near campus, so I was seeing people with disabilities all over the place. Then I remember going to CIL [Center for Independent Living]. No, I went to a conference. I joined the Rehab Association, and I went to a rehab conference and met Ed Roberts. He was speaking. I think at that point he had just become the director [California State Department of Rehabilitation]. As I talked with people about jobs in the Department of Rehab, people kept telling me, "Oh, well, we don't know what's going to happen because this radical guy has just been appointed."

Again, even within the Department of Rehab, which was also, I mean, that was the last thing I was ever going to do. I had worked for the government when I first got out of school. I was never going to work for the government again. I knew. It was, like, I couldn't find a job. It was, like, I couldn't find anything that appealed, that I got offered. I was very depressed.

Anyway, so then I met Ed, and he said, "Well, go over to CIL." I was kind of afraid to go to CIL because everybody was so visibly disabled--all these disabled people that were running around in their wheelchairs--and it was just intimidating. The whole thing was intimidating. I couldn't think of walking in the door [chuckling] and saying, "What do you do here?" and "Do you have any jobs?"

Anyway, so then I met Ed. Of course, his personality is so warm. Was so warm. He was so engaging. Everyone crowded around him, talking to him at this little conference. It was someplace out in Concord or someplace. He said, "No, no, no. Go over. Oh, yeah. We need rehab counselors." You know, always inclusive. He said, "Go over. Ask for Cathy [Catherine] Duggan. She'll show you around. I'll tell her to expect you."

Of course, that never happened. I went there. Cathy Duggan wasn't there. I went there again. Cathy Duggan didn't call me back. I mean, it was, like, oh, God! You know? But by then at least I had walked in the front door and I had seen the receptionist and I called on the phone a few times.

Now, I can't remember how I decided to volunteer there. All I remember is that I ended up in housing because I had had this three-year career in finding people housing. I think when I finally got there and connected with somebody, they referred me to Peter Leech because Peter Leech had that simulation program, simulating disability. He was doing the training for counselors from Nevada and someplace else. People would come in for a week. You'd use a wheelchair and experience environmental things and there were sessions where people would come and talk to the group about their disabilities. Then you had to go out in the community and do things in your wheelchair to kind of simulate the experience.

So I met with Peter and he said, "Well, you know, our grant is just about over, but we have one class coming up, so why don't you be in the class?" You know, "You're a rehab counselor. You can be in this class with these rehab counselors that are coming in." I think I had started volunteering before that. I can't remember the sequence. It doesn't matter. But I guess the point is I began to feel a little more comfortable at CIL. I knew Peter Leech. He was nice to me. I knew the receptionist [chuckling]. She was nice to me. I kind of found that pretty much everyone was nice to me. So I think I had, really, that experience of all you really need is a little exposure. It's like there's nothing really scary about this whole thing; it's just that people are afraid because they have no experience with people who are different from them.

Anyway, so I started volunteering with Frank Foisie. My job was to go out and check out these apartments. They would get listings. He had some connection with the UC housing office. He would get listings of available apartments and houses. My job was to go out and check out whether they were accessible or whether they were pretty easily modified to be accessible. That's what I did. I ran around in the community and looked at these places.

I remember one of the first things that happened was I got in big trouble with O.J., the guy who was the parking lot attendant. Do you remember O.J. McDonald? He was just such a nice man. Later, I was really friendly with him. But I remember when I started volunteering, again, it was just this

fear of this whole experience. He yelled at me because I was pulling in and out of the parking lot too much because my job was to go out. It was, like, "Well, what are you doing here? Are you going to be parking here or not? This isn't what we do." You know, "You park here all day or you park on the street. You're too much trouble." It was weird.

Judy Heumann's Assistant and Grant Writer for CIL, 1976-1978

McMuldren: So I did that for a while. Then Carol Fewell was Judy's assistant at the time. She was leaving.

[tape interruption]

Bonney: Okay, so you were talking about Carol Fewell.

McMuldren: She was going to leave so I applied for the job as Judy's assistant. By this time I was kind of integrated into the group at CIL, and I had gotten to know some people, working there, volunteering for Frank. I want to say I think I started working in January. I didn't volunteer for very long. A month, two months. Because I know I looked for a job for a couple of months; then I started volunteering while I was still looking for a job; then I started working for Judy. I think it was in January of '76. Maybe not.

Anyway, so Carol kind of oriented me to working with Judy. Judy came in, she interviewed me, and the only interaction I had had with her was that she was looking for a place to live. I had this place I was going to go with her, when I was working in housing. I remember I was on the phone, and I was asking somebody some questions about their house. I don't know. Measurements or stats. I don't know what I was asking them.

I remember Judy--it was, like, she was available to go look at this place, and it was, like, she came wheeling around, and she, like--I mean, she was just so impatient. So my first impression of her was, Oh, my God. This woman. She was so impatient. I was trying to finish my phone call. She was just, "I'm ready to go. When is she going to get off the phone? I'm ready to go." She's, you can't imagine. She was, like, alive.

That was the only time, really, that I had met her. I went with her to look at this apartment or house or whatever it

was, and then this job came open. You know, I knew people, but I didn't know people well enough for them to say to me, "Oh, my God. What are you getting into? You're going to work for Judy?" Instead, Carol was real professional about it. She told me what the job was. "Judy's not here very much, but she'll keep you busy because she's always doing a thousand things and traveling and all that."

It's kind of interesting. I was thinking about this. Now, where I work, we have operations people and marketing people. They're defined that way. It's interesting to me that twenty years later, I'm in the same environment, very similar kind of environment in terms of the way the organization is structured. At the time, it wasn't really conceptualized so well. I mean, maybe it was for some people.

Bonney: At CIL?

McMuldren: Yes, at CIL. I mean, certainly there was an understanding that Judy was the person that was on the road. But, where I work at CARF [Commission on Accreditation of Rehabilitation Facilities], people are defined as national directors, and their job is to be out there talking with people in the field and marketing CARF, which is basically what Judy did. Judy's job wasn't really defined that way. Her title was deputy director. She was always involved in the day-to-day operations at CIL, very much, and always got involved in any decisions that were being made about new things that were going to happen at CIL or whatever.

But really, looking back, I think that she was basically a marketer. That's what she did. Her job was being the outspoken disabled person who sat on boards and was on advisory panels, and her job was to basically get people who had disabilities to the table in all these organizations that were supposedly serving people with disabilities or doing projects for the disabled or whatever. She was the one who had the nerve to go and be that only person there who had a disability in so many rooms.

I would go to some meetings with her. Sometimes I would travel with her and do her attendant work, and then I would go with her. I remember I got to go to the White House Conference on Persons with Disabilities. You know, big conference, one time. We took this whole entourage of people. It must have been in '77.

Pat Wright and--no, Jim Pechen went, so it was after we had started the paralegal project. Judy and Dick Santos and

then I went. I don't know if we had more people than that. But at least the five of us went. We went to D.C., and we went to this conference. One time I went with her to Boston to be on an advisory group for a television program. These people had gotten funded to do this television program. It was through the special ed office. I don't think it was called OSERS [Office of Special Education and Rehabilitation Services] at the time. I think it was called Bureau of Education of the Handicapped, BEH.

Bonney: Yes, BEH.

McMuldren: They had a grant. There were actually some other people who had disabilities on that advisory board, at least, so I went to that advisory board with Judy, and that's where I met Don Zimmerman. Oh, yes. Anyway, it ended up that I traveled with Judy and I worked with her really from whenever it was in '76 until we set up the Grants and Contracts Office. Actually, I think I can figure this out. I was going to figure this out before you got here. I think it was '78. So I actually worked with Judy from the beginning of '76 to October of '78.

Bonney: So about two and a half years?

McMuldren: Yes. Basically, she was a national figure. She was always going to Washington. She had been--which I'm sure you have heard before--that she had worked as a staff person to a senator.

Bonney: Which senator?

McMuldren: No idea. I want to say Jim Jeffers, but I think he was just somebody else that she worked with a lot. I don't really remember whose staff she had been on. And with Lisa Walker, I think was her name. Then she went to work for the Children's Defense Fund, Lisa did. But she and Judy stayed really close, so she was always being invited out for different events that we would have. I remember she was at the White House Conference in Washington.

Anyway, I did this work with Judy. It was interesting because I remember she was gone a really long time. I mean, in my memory it was forever before she ever even was there, and I had this job!

Bonney: You had the job before you had even met your boss, yes!

McMuldren: Well, I met her and I had interviewed with her. I mean, she had offered me the job, but then I was just sort of keeping

myself busy. I was reorganizing all these files and trying to clean up her office. I found out later that was going to be, like, this ongoing struggle of trying to stay on top of all this stuff that would come in because everybody in the world wanted her to be on their boards and come to their meetings and speak at their conferences.

So it really was a system of trying to manage the volume of work that would come in or the volume of information that would come in. What would happen would be Judy would be gone; she'd come back in the office; she'd be on the phone all day. She would just be on the phone constantly. The thing was it was really hard to do very much of her work for her.

She would come in; she had made all these new contacts; she would have all these new ideas, and then she would be making all these calls and getting all these calls from these people. Or she would be talking to people who wanted her to come speak somewhere. It was always a little like, "I'm here and I'm supposed to be her assistant, but I can't really answer this question on her behalf. I don't know," you know? "I can tell you if her schedule is available." Beyond that, it would be, "I don't know."

I think what happened--I'm saying this by way of saying--so I got more and more into working on grants, you know, writing things for CIL, doing other projects, doing other things because I couldn't really speak on Judy's behalf; I couldn't function on her behalf in the organization. So I would represent our office, Judy and me. I would represent us with Phil [Draper] and Mary [Lester], whatever. There were kind of like executive meetings at CIL, if you want to call them that. Sort of management meetings.

A lot of times I'd be conveying information to Judy when she was on the road or updating her when she got back. Then, like I say, she would always come back with all these ideas, all these contacts, all these ideas. I think a lot of what we wrote in terms of the grants--you know, they would come out of ideas that came up while Judy was out because she would come back; she had met somebody--

One of the grants I worked on was the KIDS [Keys to Introducing Disabilities in Schools] Project. It was an education program to go into the schools and talk about disability. In fact, it might even have come out of the meeting in Boston with the group creating the television program. I have to look at this [looking through papers]. When did we get that grant?

[tape interruption]

McMuldren: So we wrote this grant for the KIDS Project, and it was a big federal grant for three years. We hired a bunch of people. I remember--what I started to say was--Judy would have made the contact. I mean, they would want to fund us. We would write these grants, and Judy would work on the program development and planning for the grant funded activities.

A lot of times I would draft grants. Mary taught me about grant writing. Joan [Leon] taught Mary, and Mary taught me. I didn't particularly work with Joan. Joan was out of the office most of the time. She worked out of the office, and then she went to Sacramento and took that job as assistant director. I remember when she left. I remember Mary was just hysterical that she was not going to be able to do all this fundraising writing without Joan.

But she did. Then she dragged me into it and started teaching me on how to write these grants, and so I would write these drafts. I can remember working a lot. Phil would review them. He would kind of give us a framework of what we could do, what would be reasonable, what he thought CIL could respond to.

So it would be, like, Judy would come in with these HUGE ideas [chuckling] and all these contacts, and I learned to write grants and sometimes people will say, "Oh, my God. You've written so many grants." "Oh, my God! You have an 80 percent success rate!"

Bonney: It's huge.

McMuldren: It's huge. But I always felt, and I still do today, that it was because people wanted to fund us. I mean, "if you can write a sentence, we're going to give you this money." [chuckling] "Tell us what you're going to do." But the brilliance of CIL was the way that all this funding worked together. The thing that I learned, and I don't know who was responsible for that idea, but the way that it worked was we would write--

I mean one of the projects I worked on was a VISTA [Volunteers in Service to America] grant. I wrote this grant to VISTA. Now, again, I think it was Judy's idea. She had some idea about, "You know what? We could get--"

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McMuldren: --people to do this service." Or we'd get the money for people to do services, but it would be for three years and then we wouldn't have any funding to keep the service going. So the thing I remember, the focus of all the work I did there, the thing I remember was we were always struggling, putting things together.

Back to the VISTA grant, as an example. We wrote this grant and they gave us ten VISTA positions to be at CIL. VISTA was the internal Peace Corps thing. VISTA paid these folks. Then we got people, people who had disabilities who had benefits, and then their VISTA stipend--because it was stipends--would supplement their SSI, and so they actually had almost a decent amount to live on [chuckling] while they worked at CIL and they were VISTA volunteers.

We got ten people. I probably have it here somewhere. I think I do. What the positions were. But I know you had asked me originally how did we fund deaf services. I know we had two VISTA positions that we put in deaf services, and then we had somebody in advocacy, we had somebody in development, and we had somebody in blind services. That was the kind of thing we did constantly. We would get these grants, and we would get a grant that would fund--maybe the focus of the grant was wheelchair repair--but then we'd also bring in a couple of peer counselors. One would work in one department, and one would work in another.

When funding would run out, when one source of funding would run out, it would never mean that that department remained unfunded because there would be somebody else who was funded by some other source. That was how we just kept working it. You know, you talk about quilting. It was a patchwork. The struggle was that the grant funding really didn't cover the indirect costs. So there was the issue of getting staffing covered, but then there was the indirect.

That's the other thing that I just vividly remember. I remember this one time where the board--there was this guy, Peter something--I think his name was Peter, he was an attorney. You probably have his name in the materials. I remember being in these meetings in Phil's office, and it was with a couple of different board people. They were, "No, we're going to be going out of business because we are running this huge deficit," and it was all about indirects.

The other thing was we had this general fund, and we would always say positions were covered by the general fund. The general fund was donations or extra money that came in from

grants that was somehow--I don't know--extra materials money. I don't know what it was.

Anyway, so it was donations. At some point, the board at this point that I'm remembering, this one guy was an attorney. He was flipping out that we were running this deficit and basically started this movement to fire Phil. So the board was going to fire Phil, and they were going to lay a whole bunch of us off. I was one of the positions they were going to lay off.

This is an example of the general fund--they brought Judy in, but they really didn't have funding for my position. Anyway, I remember this board meeting. I remember these meetings we would have in that dark back room of CIL years before it was renovated. It was just like this big warehouse, dark room. We'd go back, and the board meetings would be there, and everybody would sit in a circle.

Anyway, I vividly remember that meeting. The board was--they were basically, "We can't live with this deficit. We're going to go out of business." You know, all of these positions were going to be let go. Honestly, I mean, my memory of it--again, like you say, who knows what the real history is. We didn't have a camera in the room. But my memory of it is--again, Judy being just such an incredible saleswoman. She basically talked them out of it, you know? I mean, it was not only Judy, but a number of people spoke.

Oh, and I remember I was crying and I was so humiliated that they were going to let me go. I was just devastated. I remember Lynn Kidder standing up and saying, "Look at people around the room. Some people are furious and other people are crying. How can this"--whatever--"We've got to remember why we're here and what our work is all about." She could be really radical, Lynn could be. She gave a really good speech and Judy did.

Anyway, I remember this particular guy who was the attorney. His career was at stake. He basically had a lot to lose, and he was saying, "If I'm going to be on a board, I have liability on this board, and I can't be a party to a business that isn't on the up and up" or whatever.

Oh, because that was part of it. That was part of it. There was some thinking that, you know, it was illegal, some of this stuff that was going on in terms of the way things were being funded or whatever. The guidelines for the grants were--and probably, you know, thinking back, that was probably a precursor to setting up the grants and contracts office, that

things were just so--I mean, I had no real administrative ability. I had worked. I had a master's degree. But as I already told you, it wasn't in administration. I think there was a lot of that.

It was, like, Judy was so fabulous at going out and making contacts for us and selling people on the idea, and showing people that a person with a disability could represent people with disabilities. It didn't need to be "these people need taking care of." She demonstrated that so well that everybody really wanted to help us. There we were. But there was really nobody who knew how to make it really work financially and make it be really a viable business. But, you know, despite all that, we did it. We just kept going.

Department of Rehab. I mean, for whatever you've heard, the main person I worked with was Ramon Jimenez. One of my jobs when we moved into the contracts office was I did the grants from Rehab Services. Mary did city-county. I did Rehab Services and federal. We only had a couple federal. Then we both did foundation and corporation things--again, as somebody would say, "We've got to write a proposal for this. Some foundation wants to give us some money, and if we can come up with something, they'll give us money."

But, of course, nobody would give you the money you needed, which was just flat-out money to spend the way you needed to fill in the gaps, to pay the indirect. So what we did, which I guess in looking back was so brilliant--and I wouldn't know who to give credit--maybe Joan, was just this way of putting all these different sources together and funding people in various departments to ensure the continuity of these services. It was really quite brilliant.

Then, of course, there were also all these folks who lived on disability, who worked at CIL, who didn't collect salaries. So that was part of it, too. That was the other way that things kept working. One of the questions you'd asked me was how did deaf services start. Deaf services started really because of Dale Dahl. I'm sure you've heard about him. He was that guy who was deaf originally. I mean, he was born deaf and then he was in an automobile accident and then he became a quad so he needed services at CIL. He needed attendant referral, he needed wheelchair repair, but his only communication was sign language. So he started coming--and the thing about--I mean, he's gone, too. [crying]

[tape interruption]

McMuldren: I realize I'm going in circles. It's like everything reminds me of something else.

Judy Heumann's Internal Role at CIL and Her Work Style

Bonney: You talked a little bit about Judy sort of being this outward, PR-information kind of person. How much of a role did she play in in-house issues, in in-house decisions and management kinds of things?

McMuldren: Well, [chuckling] I think that's what I was saying was interesting. She wouldn't be there, and yet she'd come back and she very much wanted to be involved in day-to-day decisions. She had very strong ideas about the direction she wanted CIL to go and what she felt we ought to be doing. Like I say, comparing it to where I work now--I mean, if I had had this experience back then--I probably would have been a person who would have been speaking up, saying, "You know, we need to just divide this." Because, in fact, Phil definitely ran things day to day, but Judy really wanted to be involved in that, too. So she would come back, and she would get right into whatever was happening day to day.

So often she would come back with the contacts to go in some direction, then she would have ownership of that. Like, it was her idea to start the paralegal program. I think we got a CETA [Community Education and Training Act] grant. I remember she and I did this concept paper or started writing this grant or whatever. I mean, I talked to her about this in recent years, and she vividly remembers being there at CIL late one night, writing this grant. I don't remember that!

The thing I remember was it was a CETA grant, and Mary really knew CETA. So I remember having some concept and then I remember working on it with Mary to actually finish it so it was appropriate for CETA. But at any rate, we got this CETA grant for paralegal. I mean, that was Judy's baby.

Bonney: Now, tell me what the Paralegal Project was.

McMuldren: It was to train people who had disabilities to be paralegals.

Bonney: And to work with CIL, or to go work--

McMuldren: No. Well, let me think about that. What came out of it was DREDF [Disability Rights Education and Defense Fund].

Bonney: Oh, DLRC? Originally? Disability Law Resource Center?

McMuldren: Oh, that's right. It was DLRC first and then DREDF, yes, yes. That was it. But I want to say the Paralegal Project, though, had this training element that we were going to teach people to do paralegal work. Then the idea was definitely that they were then going to be able to be advocates out in the world and that they would be able to do disability cases in law firms and whatever. I don't know.

I remember Gordon Lewis worked there, and Jim Pechen got hired to be the director. He was a veteran, and he had been running this veterans law project in San Francisco. So he was recruited, or he applied, and he was hired to do the paralegal project. Yes, and then DLRC. Now, how did DLRC run out of it?

But one of the people who came into the project--and I can't--let's see if I can find a program description in my notes [going through papers]. One of the people who came into the project was Bob Funk.

Bonney: Right.

McMuldren: Yes. Okay, I found the KIDS Project. Okay. Bob Funk, I remember him calling me. He was someplace else in California, Sacramento or someplace. He was finishing law school. He had met Judy or something. Anyway, he was interested in coming to work at CIL. I remember I developed this whole relationship with him on the phone. He's one of those people. He just kept calling me and checking in with me. Did we have the funding yet? You know, were we accepting applications.

So I want to say he started as a paralegal in that project even though he was already an attorney. I don't remember whether the Paralegal Project then became DLRC. Because I know DREDF was Bob's project. After he got in and he was at DLRC, I mean, he was really the one who wrote the paperwork and incorporated it and said, you know, "This follows the model of other civil rights movements. We need a disability rights and education fund. That's what we need."

That was really as I was leaving CIL. I was never really involved in that. But I knew at the time when he was doing all that paperwork, and convincing Phil and Judy that this was the way we needed to go, and we did need to incorporate this separate--now, was DLRC incorporated? Do you know?

Bonney: I think it was DREDF. That's what I've heard.

McMuldren: Yes.

Bonney: What was Judy's work style? You worked for her.

McMuldren: Right.

Bonney: What was her work style like?

McMuldren: Well, she is so high energy and she's so bright. I think she was really hard for a lot of people to deal with. God knows, I had my hard times [chuckling] working with her. She would have so many things she wanted to do, and she would have so many ideas. I mean, it felt scattered a lot, and it felt just overwhelming to me. I was talking about the mail and how before she even got there, I was trying to sort through all this mail. I didn't know what to do with it. I was filing it and separating it and trying to make some sense out of all this stuff.

That's what would happen. She'd be on the road, she'd come back, and then I can remember just, oh, many, many, many nights that Judy and I would stay at CIL because, like I was telling you, she'd be on the phone all day, and then we would work all evening. I mean till eleven o'clock at night. We'd sort through--in fact, I can remember Jan[et] McEwen--she would say, "Oh, God, Judy worked late last night," because you'd come in to these presents in your mailbox.

What would happen would be that she would have all these contacts and so things would come in the mail, and then we would write notes to people and say, "Call this person. This is a contact. Follow up with this. They're looking for information about this." Or "They want a representative" on this or whatever. She drove people crazy because she had so many things going.

That's why I say I just give her so much credit for what she did because she really met with a lot of resistance for the work that she wanted to do and the direction she wanted to see CIL go. I mean, we were working really long hours just to keep our heads above water on the stuff that we had to do day to day. From my perspective, it was keeping funding just to have supplies and to keeping things going day to day. I was very much involved with Mary and Lynn. And then CIL started the development office.

But anyway, Judy's work style, I think, it was very energetic and yet scattered. We would talk about how she needed ten people like me. I mean, I could do one piece of it

and then I would just be so overwhelmed. I can remember being angry at her a lot and feeling like she didn't appreciate all the work that we did. It was just always more. You just needed to do more and just needed to do more. There was never a minute to relax and be happy about something that had been accomplished. It was always like there were ten more things to be done [chuckling] before the end of the day.

I can remember being, for example, like now. I'm a person who is very healthy. Have been very healthy really most of my life. But I remember at CIL I would get these terrible sinus infections and the flu because I would work such long hours, not take care of myself, and always feel like no matter how much it was, it was never enough. We couldn't do it all.

Partly, I think, it wasn't just Judy. It was really the outside world wanting so much from CIL. It was well, how do you do this? How can we replicate this in other parts of the country? I mean, we dealt with people--oh, my God. The tours. It was constant. People who had met Judy or Ed somewhere, and they'd come from all over the country, all over the world! I mean, I remember scheduling tours.

Oh, and I did that when I worked for Judy. Always setting up these schedules for people from Sweden, people from Italy. I mean, people from all other countries coming in and setting up these schedules for them, going around to all the different departments, getting the spiel of what they did, how they did it.

I remember advocacy was just a puzzle to people. That was something that people were just fascinated with. It was, "My gosh, these people with these severe disabilities, and they learned all this stuff about Social Security? Nobody can figure Social Security out!" We had two or three people, and that's what they did.

Like Greg Sanders. There's another one that's gone. He was a genius. He knew the disability regulations of Social Security better than Social Security did. He absolutely did. That was his gift, that he was able to read this stuff and understand it. I don't know. I know Jack [John Rowan] worked there, too. Greg always had the reputation of being the genius. I mean, everybody loved Jack because he was just such a nice person. Not to say that he wasn't competent. He was very competent. He was competent and he was nice. He had such a beautiful face. Such a warm person.

Bonney: Still does.

McMuldren: Yes. He was more like the counselor, and Greg was more like the guy who had figured out the information. Greg wasn't so warm, but he knew the stuff. I remember he had a power chair that moved: he had one of those that went really fast. He would fly through the office. Very little time for pleasantries. He was very "onto the business." But that was, like, one of the fascinating things.

Then deaf services, too. I think CIL really laid the ground[work] for people who had hearing impairments to be involved in the independent living movement. Part of what I remember about that was we tried to work with DCARA [Deaf Counseling Advocacy Referral Agency]. We tried to work with GLAD [Greater Los Angeles Council on Deafness, Inc.] in L.A. Leo Jacobs and--I can't remember who else--but Leo Jacobs was the person, a man who was deaf, who was on the DCARA board, and he got involved with CIL. I don't know if he was ever on the board, but I know he would come to board meetings. He's somebody who turned around. I mean, he didn't want any part of this, and he didn't understand--

I think there was a fear that somehow CIL was going to steal money from deaf organizations. I don't know what it was, but it was paranoia, definitely. It wasn't about forwarding rights for everybody. There was some kind of fear that people who had physical disabilities were such rabble-rousers in Berkeley, like, what were they doing? You know, just distrust that there was some motive that wasn't on the up and up [chuckling] or whatever. I don't know. I was so much involved in funding. I don't remember if--my memory of it had to do with funding. But it doesn't matter.

But anyway, deaf services would be some place that all these visitors would come. They were clear in the back of the back room, and we would take them back to the back of the back room, and they'd do a little song and dance about deaf services and what they did and what kinds of services they provided to people. The VISTA workers that came in under that VISTA grant were both deaf, had grown up deaf, and Dale.

I want to say Dale was pretty much the only person who was deaf who had another disability. Maybe that's wrong, but he was the one who started it because he needed the services. He came in and he taught everybody sign language. He really bridged between CIL and the deaf community. He also was just such a dear person. There was nobody who couldn't like him. I mean, he was just so kind and gentle. I mean, I can remember him one time saying to me, "What has happened to your sign language? Your skills are really down." [chuckling] I mean,

he could say that to me in a way that was just like concern, "Why haven't you been signing?"

But he came there and he started sign language classes, and he just taught us all how to sign. Then everybody at CIL started knowing sign language. Some people were better than others, but everybody helped everybody and interpreters. Then, as we got interpreters there, they really helped all of us that were learning to improve our skills.

But anyway, so, yes, Judy would bring in all these people from all over the place all the time [chuckling]. I mean, I guess it's kind of like the way I'm talking about it is the way I felt. It was just, like chaotic. It was always chaotic. It was one thing was happening, and then you were off doing something else, and then suddenly there was somebody there unannounced from Sweden [chuckling]. I don't know, it was just, like [screaming], "AAHH!"

I can remember getting really angry and just not being able to cope with it at times, and then other times just being so--I mean, it was just such an exciting place to be. I just believed so much in what we were doing. It just made so much sense. Just seeing people in that way that I had never been exposed to, because even though I had gone to school with people who had disabilities who were very severely disabled in my program in New York, they weren't alive like people in Berkeley were. They were so dependent on transportation and all these inaccessible places we were. It was just--I mean, looking back--there's just such an incredible contrast.

Judy Heumann's Goals and Vision for CIL and Her 504 Sit-In Activities

Bonney: Let me ask you another question about Judy. What do you think her goals and vision were for CIL and for herself?

McMuldren: Well, I think her goal was definitely to bring people to the table, people who had disabilities, to be--you know, full inclusion. That was her vision always. She had that from her early upbringing. You know her whole thing about suing the school district to be a teacher and all that stuff. She had this circle of friends that she had grown up with, like Steve Hofmann and Neil Jacobson. Nancy D'Angelo. That was the other one. Nancy D'Angelo. They had grown up together. I mean, they were like sisters and brothers. That kind of--they didn't

always get along--but really deep, deep connection. I think she still does. I mean, she really has this vision that people with disabilities are really her brothers, her sisters and brothers, and such commitment and love for other people with disabilities. I don't know. She really wanted people to have a chance.

She had the gall [chuckling] to put herself in those places, to be the one who would keep saying, "I can't believe there's not another disabled person in this room." Or "I can't believe you've invited me here and you want to do this project, and I'm the only representative of the people that you're going to be serving." I just would be with her so many times when she would say that.

Bonney: What would the reaction be of the people in the audience or people she was talking to when she'd say that?

McMuldren: That's what was so amazing about it, and maybe that's just Judy's gift, because she didn't alienate people. She could do it in a way--I mean, granted, people get angry. I know there was a time that the people in the DR office in Oakland, I remember this one meeting where they came over, Henry [Leng] and a bunch of other people, and they were just pissed. I mean, they were just pissed. I can't even remember at all what it was about.

Definitely Judy had this reputation among certain circles where people kind of talked about her behind her back. She was just so outspoken. But I think in the community of people who were trying to work in rehab, who really wanted--I mean, they were in rehab because they really believed in it and they really wanted--to do service. Those folks basically would respond to her. They would get it. I mean, people would get it from her that you can't be doing this without getting some input from people with disabilities.

I was just thinking about the Office of Civil Rights. She also had some contact. Hal something-or-other. I remember, like, he was always inviting her to meetings. Oh, and I remember--even back then, in the seventies--talking about should they go for an amendment to the Civil Rights Act. That was way before anybody was talking of ADA [Americans with Disabilities Act].

Bonney: Who was talking about this?

McMuldren: Judy never believed they should because she felt that people with disabilities would just get swallowed up. That it would

be some little amendment and nobody would pay any attention to it. So she always had the vision that there should be separate legislation.

Well, yes, then you get to the 504 [Section 504 of the Rehabilitation Act of 1973] sit-in and all of her work there. She had the idea that--well, the other thing she knew was having done this work as a legal, as a staffer, she knew the legal--I mean, she knew the legislative process. She understood how to get legislation passed, and she understood the difference. Nobody else knew the difference between going for civil rights legislation through the Civil Rights Act, or was it state laws. I mean, she knew all that. And she knew the significance that there were no regulations for 504.

I really don't know how many other people really got it, that there was a Rehab Act, but it really was kind of worthless. It had been passed in '73, and, like I say, I don't know--I don't know if other people in the community understood --I mean, I really don't know. Maybe the people in advocacy that were more legal minded also--but Judy--she had wanted to go to law school, and she definitely had that perspective, that you work through the legal process. Yet, when it came to the fact that it really wasn't working, she was ready to do what it took to get those regulations passed.

I think that's a good example of the difference between Judy's and Phil's style because Phil was--well, he was more the day-to-day person. You know, keep services flowing, keep people on staff, keep things running smoothly. It was appalling that she was going to do this. I don't even know how much people knew that--I mean, I can remember her saying, "We just might stay. We might refuse to leave." I was, like, "Not me!" [chuckling]

Bonney: Tell me what you saw Judy doing before the 504 sit-in and then during the sit-in. What role did she play? What did she do?

McMuldren: I remember her being in Washington, and I remember news coverage of her at [Health, Education and Welfare Secretary Joseph A.] Califano [Jr.]'s house with a bunch of people and--

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Bonney: Bette, what organizing activities did you see Judy doing prior to the 504 sit-in?

McMuldren: Well, when I think of organizing now, I think of involving, maybe, working all your contacts with a bunch of different

groups and things like that. But my memory of it was much more--it was such a family at CIL. Like I was talking about her incredibly deep relationships with some of these folks. It just really went back. I mean, she probably, since she was in grade school had always been the one in charge of that group of folks. Judy decided she had to convince them. She had to convince her friends and her family--not her blood family--but this family of people with disabilities. But it was more that kind of thing. It was more within CIL and just kind of everybody getting--you know, talking amongst all the people there.

Like I say, I don't think of it as organizing like I would now, of organizing in terms of a lot of other groups or getting support. Maybe she was doing that, but I don't remember it. The part I remember was just everybody at the office kind of buzzing about "I'm going to go down there," and there was going to be this meeting. Then the thing I remember was about people deciding to stay, and I just couldn't do it.

Bonney: Were you in the building with them?

McMuldren: Yes. I went in to the original meeting--

Bonney: What happened--

McMuldren: --and then I left. I don't remember. I remember there were a lot of people, though. Did it start with a meeting, a protest to begin with that we took a bunch of people and that's why there were so many people? Because the thing I remember is there were a lot of people. I mean, the original night of the sit-in, there must have been at least twenty people in the building at that point, or fifteen. I know more people went in and then stayed. Then people would leave and come back.

Then what happened was then some of us who didn't want to stay in the building did this vigil outside, where we would march around outside. I remember this one night being there and, well, I remember two really interesting things about being camped outside was that the television news came. I remember this one time the news came, and things had basically shut down for the night. I remember we staged a little [chuckling] demonstration for them--the news guys knew it; we knew it. They wanted to put it on the news that night, so there were ten or twelve of us there. We walked around in a circle and we had signs, whatever, and [chuckling] chanted, so they could get us on the news and talk about all these people that were in the building.

I remember that was definitely after the Paralegal Project had started because I remember Jim Pechen was--oh, and he was a big influence on Judy in terms of planning that, I think. Because they were real close at that point. Yes, because he stayed in the building. He definitely stayed in the building.

Bonney: Oh, he did?

McMuldren: I remember Jeff Moyer stayed in the building. The thing I remember was coming back the next day. So I had this idea of, Well, okay, I'll protest outside the building at night, and then I'll go back and I'll work from the building with Judy. I remember walking out of the elevator in the morning, and everybody was there in the lobby of the elevator, on whatever floor they were on. They all just broke out laughing because I was the only person who came off the elevator, and they were all chanting, whatever they were chanting [chuckling]. Then they all just, like, burst out laughing. "IT'S BETTE!" [laughing] We don't have to do it for her. Right.

Then, after that, basically I worked at CIL. There was a skeleton crew at CIL. I was just more comfortable with that. So I worked at CIL. I'd go over some evenings and go over on the weekend. I remember there was a big rally outside, and I remember at one point we got these telephones and we were going to smuggle telephones into them, and then we found out that they basically had total access to the phone lines [chuckling]. That was not a problem.

Yes, but see, now, that was where Judy knew what to do. Truly, I just don't know that anybody else did in terms of how to pull that off and to stay there. Just like I say she was able to engender support from people, all kinds of people. That was kind of like the thing of having access to the phones. The exterior presentation of this was this radical sit-in going on. But there was also people who were supportive inside, who let them use their phones and who really did understand and were helpful. They never publicly said--their jobs, I guess, would have been at stake. But they really were supportive.

She's just so charming. She's so smart, and she's so quick. She's able to just catch on to what's going on real fast, and say things that endear people to her. She has that kind of New York way. She can just really charm people. I think she used that. She really knew how to use that.

Then the other thing about Judy is also--she looks like she's twelve years old. She has such a young appearance. I

think that was part of it. She would disarm people by being so charming and so bright and looking so young and being so wily. I mean, just being so smart. Really knowing what she was after with these interactions with some of these people. You know, I think people used to call her manipulative. I didn't really see her as manipulative. I really saw her more as charming. She used her skill. She used her skill to make people feel comfortable, to get people thinking.

Even with me. I would go through these times where I would just think, "I can't do any more work. She's going to drive me to an early grave." She would come back, and she would have an idea and she would talk me into it. I mean, it would be like, "But we got into it for this reason," and "Oh, this person, they're really ready to work with us, and if we do this, the next thing will be" whatever. There was always the bigger plan.

So as far as what did she have in mind, I would think that her dream is probably still evolving, but certainly she had the idea that there would be independent living programs all over the country and that they would be run by people who had disabilities. I think even then she had the vision of where the control needed to be. I can remember anywhere we would go, we would always go visit, if there was an independent living program, no matter what, we would always make time to go visit there.

I can remember going to this one program with her one time, and there was a woman who had a disability, used a wheelchair. She wanted Judy to--I mean, Judy basically came over and she wanted Judy to talk about--oh, God, I can't remember what it was, but something like their personnel policies or some kind of sort of mundane, nit-picky kind of stuff, some kind of procedures on something. Thinking back, it might have been how they ran their attendant referral or something. "First the attendant calls. And then we do the screening."

Judy was, and this was sort of the other part, she was disarming in that she basically blew this woman off. It was, "I haven't traveled here to talk to you about your procedures." So she knew, even then, as a young person, she really knew that her job was to really motivate people and to teach people. It would be, "What do you want to talk about in terms of political action? Talk to me about that. What needs to be changed in your community? What are your struggles with your Department of Rehab?" "Talk to me about that. Don't talk to me about some stupid procedures."

I can remember this woman just being, just watching her just be crushed, just being told in such a direct way, "I'm not wasting my time on procedures." So there was that part of being so direct. But then, within the next half an hour, motivating this woman like she'd never been motivated in her life, by being really talked to as a person who doesn't need to look at the little procedures, who needs to talk about how she wants her life to be, and what is she entitled to.

Bonney: Incredible.

McMuldren: Yes, it was just incredible to observe.

Department of Rehabilitation and Its Relationship With Judy Heumann

Bonney: Let's go back just a minute, if we can. You just mentioned, very quickly, that you remember meeting with Judy and the DR people, and you mentioned Henry Leng as one of them. What was Judy's relationship with DR and those people? What did they work on together? Tell me a little bit about that.

McMuldren: I remember working with Ramon on the fee for service. One of their themes had been that they could help us by purchasing services. So people who had cases at DR could buy, the DR counselor can buy for them, some of the services that we offered if we would just set up a fee for service, and then they would charge flat rate. So I remember that, and I remember working on that schedule with Ramon and really not having--I think this was after we had set up our grants and contracts office, but I remember really having heard about it for a long time and then ultimately it was my assignment. I was either going to get it done or it was never going to happen.

It was, like, not having any idea how to do it. I remember having just no idea how to do it. I guess that's my other memory of really not knowing how to--feeling really incompetent a lot of times--how to do the paperwork, how to keep up with all of this. I remember there was a whole thing of the bookkeeper at CIL--suddenly CIL had a million-dollar budget--and the bookkeeper had no bookkeeping experience [chuckling].

Then, DR bailed us out basically and gave us a grant to hire a comptroller. So I think the relationship was definitely

one of those love-hate relationships, definitely there were times that they felt, I think the people from DR felt really used, abused, unappreciated [chuckling]. But then they would continually come around and help us. They really did. They funded us in so many ways. I mean, we had I & E [Innovation and Expansion] money and establishment grants. I mean, just pretty much continually. We were always getting those.

I think that they didn't have control over the fact that the funding structure was--you know, it's a three-year establishment grant. Get the name. You're supposed to establish something! They're not supposed to fund it forever. But they would always find ways to try to help us. They could extend it--they would end up having extra money and they'd give us money. So I think they were very supportive, really. Although I think more than a lot of the other people that I saw Judy interact with, I think they probably, on a more personal level, were offended more often.

Like that one meeting I remember. People were not happy. I think they took some of that activity at CIL really personally, like it was really--it was a real affront. "You aren't doing your job. We're going to provide these services. We're going to help people really do something with their lives and have some independence and make their own decisions. All you want to do is patronize." I think there were relationships that came and went with that group.

See, now, the thing I remember with Ramon was that he was always this kind of really laid-back, nice guy. He never sort of got hooked into that animosity. He would basically do what they would tell him to do. I mean, he was a facilities person. He would do these grants to us. Whatever he thought about them, he didn't ever seem to be negative or have animosity toward CIL.

Bonney: Did he work at CIL?

McMuldren: No, no. He was a facility specialist for DR. What were they called? Community resource specialists. That's what they were. They monitored the grants and issued the grants. They were in an office down on University. He and Joanne Bodine. They weren't in the Oakland office. The Oakland office was more services.

I think there was a struggle about getting people services for job-related things. I remember one of the big issues was doing self-support plans so that people could buy vans. That was one of the new things that was happening. What

was the role of DR? Were they supposed to help or not? I can remember Karen [Topp] being there. She had to approve these plans, I believe, that was the way it was structured. She was pretty much supportive. She would go out as far as she could go to give people their own authority to make their own decisions.

But I think there was definitely a feeling that DR could have been more liberal, that the local office could have been more liberal, could have been more supportive. I think the feeling was that they should have been able to fund more. Looking back on this--because now, since then, I've worked as a voc rehab counselor for the state of Arizona. So I'm kind of confusing what I know about the rehab laws now and what I knew then. I can't remember.

But as I'm thinking of it, I think there was actually the feeling that they ought to be able to buy attendant care. No. There was attendant care money. I don't know. I don't know. But I know some people had DR cases, but not that many people had DR cases. It was a limited number of people. But I remember the thing with the pass plans and trying to get a bunch of people transportation. I mean, their own transportation.

But then also working on the issue of transportation. CIL had a transportation program, and I remember getting a grant to buy vans, and running the transportation service and keeping drivers and keeping the vans on the road. There was always the maintenance. I think that was another one, one of the circumstances where we got the grant to buy the vans, but we didn't have the money to maintain them properly. So they were constantly breaking down. So there was always this struggle of where were we ever going to get the money to really keep the program running.

It was always this theme of, we had the vision of how to do it right, but we never quite could do it usually because of funding limitations, and then resulting staffing limitations.

I don't know. I got sidetracked. What were we talking about?

Bonney: I don't know [chuckling]!

McMuldren: You got sidetracked, too. Sorry.

Judy Heumann's Affirmative Action Stance

Bonney: Let me ask you this. You were talking about the shop, the transportation system starting up.

McMuldren: Yes.

Bonney: We have interviewed Herb Willsmore, and he told us of a story of Judy overruling his hiring decision in the shop. He wanted to hire someone, and Judy said no, that he had to hire an in-house person first, an in-house person first, which he thought was sort of her policy, regardless of what the qualifications were, seemingly. Did you ever see that or hear about that? Evidently, he wanted to hire some outside--I believe it was a man--and Judy wanted to hire an inside woman.

McMuldren: And this was to work in the transportation?

Bonney: In the transportation--wheelchair--yes, transportation, I think. In the shop, wherever the shop was.

McMuldren: Yes, that would be wheelchair repair. The memory I have of it was that CIL did, even back then, CIL had an affirmative action plan. I don't think it was required. It was a real Berkeley kind of place. You hire a person with a disability, and you hire a person who is a minority. It was always put a woman in a non-traditional job. It was anything non-traditional we could support, we supported.

When you say that, I don't remember that circumstance. But there were definitely circumstances--and we would tease about it--the sort of mom-and-dad syndrome with Phil and Judy because dad would say Yes and then mom would say No, or mom would say Yes and dad would say No. The whole dynamic between the two of them. She would go in and try to convince him of things. I think she was very respectful of him as executive director, but there were some times that she would really speak up.

Yes, I remember Herb Willsmore, and I'm trying to remember--because there were definitely people who just couldn't stand Judy at all. They thought she was just a big mouth. I don't remember whether Herb did. But there were people that just didn't like her. They didn't like her style. I'm sure there were people who thought she was arbitrary about things.

But I truly thought she had a political analysis. I mean, she was living by it. To me, that's how I see her. She knew what she was doing, and she had--and I think still today she does--she has very strong beliefs. So I think she had an affirmative action stance. If this was to hire a woman in wheelchair repair, that made total sense because she was very much a feminist, and if there was a woman that--

You know, it might have been that there was a woman who really wanted to learn those skills and maybe had an inclination, maybe had been doing something. But I don't remember that. I don't remember who he's talking about.

Bonney: Would that be kind of a typical response on Judy's part to hiring? If she didn't agree with it, she would overrule it?

McMuldren: That's not what I'm saying. I don't think so. I remember Judy going to Phil and convincing Phil. We were the kids. We would wait to see if she was able to do it [chuckling]. She would see things differently than he did a lot. But I always felt sometimes surprisingly so, that she was very respectful of his authority and she would basically try to convince him. Then, if she couldn't convince him, then it was well, that would be the decision. I mean, we'd go with Phil's final decision.

I think Phil had the respect of some people that Judy didn't. Then there were some people who just adored Judy that didn't think Phil was all that great. They definitely had their constituencies. But taking that sort of hard line control, I don't really think of Judy that way, personally. I mean, definitely outspoken, definitely had views. But I would see her more as convincing people to go with her view, rather than ever taking the hard line and saying, "Well, I'm in charge and this is how we're going to do it."

Coalition Building and Disability Hierarchy

Bonney: Okay. You also touched a little bit on coalition-building activities. You talked a little bit about starting deaf services. Could you talk a little more about other coalition-building activities that occurred at CIL? Why was it important to coalition build?

McMuldren: Oh, I think there was definitely a philosophy that we needed to embrace people of all disabilities. I think maybe some of the criticism of the movement was that it was people in

wheelchairs. I think that there was never--I think that within that community, it was inclusive, so there was definitely the philosophy of trying to make it more visibly inclusive. There was the same issue with blind services as there was with deaf services.

Blind services was the same kind of thing. There was the NFB [National Federation of the Blind] and what was it? The ABC?

Bonney: NFB and AFB [American Foundation of the Blind]?

McMuldren: Yes. Their emphasis was only blindness and visual impairment, and they were not inclusive. My memory of it is it always seemed that it had to do with fear of somehow losing something by joining forces with others.

Is it cold in here for you?

Bonney: No, it's okay.

McMuldren: But it seemed like--maybe I was just more involved with the deaf services, but we had our blind services program. One of the things that was always a problem was that it was upstairs. It was inaccessible. Space was really limited. Jeff Moyer was the coordinator while I was there, and there was a mobility instructor, Carol Wiebe, and Dan Smith was one of the VISTA positions. So he was like a peer counselor and worked in blind services. Then later we had another woman who was low vision.

They did peer counseling and mobility instruction, and they always seemed sort of separate even though they were a part of the organization. Again, there was this thing of they were upstairs, so people couldn't really visit them. I don't know. I can't remember them ever moving. I don't know if they moved before I left or not.

Bonney: Was coalition building--was it political?

McMuldren: Oh, yes. I think that's what I'm saying about these different factions and different disability groups and this fear that somehow they were going to lose something by joining together. I think that the sense of the blind groups was that they had gotten more than anybody else. They had had more success in their political efforts, and so it was kind of like they didn't need us [chuckling]. But, yes, I think it was definitely political.

Then there was the thing of Judy being the spokesperson for disability groups. I think that got taken to crazy extremes sometimes, of having to have all these--everything had to demonstrate that it was really a coalition, there had to be a deaf person, there had to be a blind person, there had to be a person in a wheelchair [chuckling]. You know, every group had to be represented.

I remember even then--and I know independent living programs are still struggling with this now--we were trying to include people who had developmental disabilities, and we were trying to figure out how to do that. You know, certainly there were people who had cerebral palsy. There were a lot of people who had cerebral palsy. People with mental retardation never really got incorporated. But there was always talk about how to build coalitions and how were we going to make that happen.

Again, that's the stuff that Judy seemed to just know. I mean, she is so good at networking, and she just never had fear about going into new situations and groups and talking about what CIL was doing and trying to invite people--she was always inviting new people. I remember this one guy, a deaf guy from some national group. He was from Gallaudet, but he was also representing some group, Al Pimental. I remember her inviting him out. I mean, I remember meeting him in Washington with her, and then she invited him out and got him all involved.

Oh, you know what it was? It was Friends of CIL, when we started doing that funding arm. Gosh, she was good at that. She would just bring people in and talk to them about the importance of all disability groups working together and--oh, and this other guy! Oh, I remember this one guy. He was some television producer that she had made contact with, and he has a disabled son who had a developmental disability, and he was institutionalized. I remember her having this guy come, and he toured. I wish I could think of who he was.

Oh, and I remember Itzhak Perlman came to CIL when I was there. Famous people. Anybody with a disability. Judy would make friends with them and talk to them about disability.

But anyway, I remember this one guy and he was--I think it was television or movie or whatever. He had a disabled son, and he came through and spent the day. This was really fundraising activity. Then I remember her saying to him, "We'd like to meet your son. Could we go visit your son?" It was, like, this door closed. I mean, it was just, "No, you'll have no contact with my son." That was it. It was so strong and so

direct. I remember Judy afterwards saying--I mean, she really got the message. It was, like, "back off" big time.

Again, her hope had been that that would be an inroad to people with developmental disabilities. It was no way. People are just so isolated and the toughest group.

Bonney: Was there a hierarchy among groups?

McMuldren: Well, I think some people perceived that. I think some people felt that there was. There were definitely factions. With Judy and the people that I knew, I really--I hung out with people in all three groups, and so--I mean, I know people would talk about that. Some people were very, very political. I remember Dick Santos, who then I later became really good friends with.

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McMuldren: The other different group--there was a difference between people who had traumatic injuries and people who had grown up disabled. There were also groups that way. There was kind of this disability macho of people that would tell their stories about how they became disabled. It was interesting because it was the people who had grown up with disabilities--this whole group from New York--I mean, this is my perception of those people I knew, they never talked about it. There was never a bravado about it in terms of, like, Judy's story of suing the school board and all that. It was really bittersweet. It was almost like it was a sad thing to have to talk about it. It was almost painful. They never talked about it.

But people who had had traumatic injuries generally would tell their stories. So in the community it would be this person had a diving accident and that person had a motorcycle accident and this person had a car accident. Oh, and there was also factions--there was a project that worked with the prisons--people with disabilities who were in prison. They were the top of the macho chain. They were the toughest! They weren't afraid to go to the prison.

Oh, I think within blindness, too, there was a difference with folks who had grown up with disabilities and people who had become blind. One of the really outspoken advocates was Mary Jane Owen. She had lost her vision. She was very articulate, and she also was so outgoing and engaging, and so she really was this spokesperson. She could talk about both worlds.

Oh, what I was going to say about the factions: I remember some of the people being really radical. I mean, some of those guys, they were guys who worked in wheelchair repair who were Communists. I mean, they were Communists. The one guy--I can't remember his name--wore a little hat.

I started to tell you about this meeting with Dick Santos, where I said--they were trying to make a decision. I'll never forget this. This is my first exchange with Dick Santos. Judy wanted to make a decision. We were talking about decision making. There was Judy and Dick, and they disagreed with Phil. I remember sitting there, you know, kind of new, and saying, "Well, Phil's the boss. Shouldn't he get to have the final word?" Dick just laid into me [laughing]. "I'VE NEVER HEARD ANYTHING SO REACTIONARY. WHERE DID YOU COME FROM?" It was, like, Oh, my God!

Yes, but, see, even with that, you know, what was Judy doing? Judy was talking to people who disagreed with Phil. She wasn't going in and saying, "PHIL, WE'RE GONNA DO IT THIS WAY!" I think she just really is a person who is a politician.

Judy Heumann's Interactions With the Media

Bonney: Let's talk about Judy and the media. What was her relationship with the media? Now, I know she was one of *Ms. Magazine's* top fifty women, as an example.

McMuldren: Yes, but that was later.

Bonney: How did she work with the media?

McMuldren: Well, you know, honestly, I have to say I think Judy is pretty consistent. I think she worked with the media the same way she works with other people, in the way that I was describing, that she's charming, she's disarming in that she'll come right out and say what she thinks, and she's articulate. I can remember this one time she was on *60 Minutes*. What I was going to say was then at the same time, she is so down to earth because this thing with--I mean, she's on *60 Minutes*, and it may have been after the 504--it might have been after 504 regs. She was in a very articulate fashion explaining why it came to a sit-in and the reason we needed regs.

But then, at the same time, it was really important to her that we watch her. I remember her family in New York

watched. She had gotten this pair of earrings for Christmas or for Chanukah and she had lost one. She lost one on the way to the show, but she left the other one in anyway because she loved them so much. I remember her brother yelling at her, "DON'T YOU REALIZE IT WAS COMPLETELY DISTRACTING WATCHING YOU WITH ONLY ONE EARRING ON?" She didn't care because the earring meant a lot to her.

So she's just such a warm person at the same time, and I think she's really genuine. I think people get that. People in the media get that. You know, because she's easy to interview. She's articulate, and she's not afraid. She just will say what she believes, you know? Yet, at the same time, not be stupid. She's political. She knows what she can say [chuckling].

The other thing I was going to tell you about was going to Judy's on the weekend doing her attendant work, getting her up so we could go into work, and then we'd go in and work all day and sort through mail and we'd divvy up all this stuff [chuckling] and tell people to follow up on things. All these ideas.

Bonney: She seemed to work twenty-four hours a day.

McMuldren: Yes. And I'm sure she still does.

Bonney: She's on the phone at four in the morning.

McMuldren: Yes, and I'm sure she still does because I know when I talk to her now it takes three or four days till we finally connect, and then invariably it's at seven in the morning on Saturday or something like that [chuckling]. Then--at the same time--what's always so interesting to me about her is that she does have this really strong tie to her family. When she comes out here, she always makes time to see me. I mean, really, right now it's not like we're working on projects together or anything. It's really just a friendship. She'll tell me about her niece, and she tries to get up to see her brother and his family. I know she's real close with her mom. It's pretty neat.

Bonney: She's got priorities.

McMuldren: Yes.

Disability as a Civil Right

Bonney: Bette, when did you first see disability as a civil right?

McMuldren: Hmm. Well, I suppose it was just a slow process of coming to realize it when I lived in Berkeley, but it was definitely in Berkeley. I mean, I had a master's degree and I didn't know it. It wasn't till I really was immersed in the disabled community that I got it. I certainly did incorporate it into my thinking in the sense that I remember when *Coming Home* came out, the movie with Jane Fonda, Jane Fonda came to CIL and recruited people as extras for that movie.

Bonney: Oh.

McMuldren: Then it came out and it was in an inaccessible theater. I remember we all went over to San Francisco and picketed the theater. Things like that. I probably maybe wouldn't have noticed or thought about. I just became really sensitized to things like shows that would feature--especially media stuff--that would feature somebody who was deaf, but it wasn't captioned. Or as I became fluent in sign language, I tried to understand people who used sign in the media or whatever.

So I was sensitized to all that, and then at the same time working with media as far as access. I forget about that. Joanne Jauregui came into deaf services. She worked with some television station and worked on getting the little insert of an interpreter. That was kind of the precursor to closed captioning that we have now. I can remember Joanne talking about what they could do, if they could do this closed captioning. She knew all about it.

Now, there's another person who is an incredible coalition builder. She was just so accepting of everybody and teaching everybody she knew sign language. It's interesting because then, years later, when I lived in Arizona, I worked in the rehab services, and I worked with a man who is deaf. He really felt it wasn't his job to teach people sign language. His attitude was very much like, "If you want to communicate with me, go learn sign language. It's not my job to have to teach you."

I think back then, though, people were really just so excited about the idea of coalition. The deaf people that were around CIL wanted everybody to know sign language. I mean, every sign you used that was incorrect, they corrected--in a nice way--corrected you and helped you learn your signs.

Anyway, so I know Joanne really worked with the media. I remember Channel 4--see, the other thing that keeps going through my mind as you're asking me these questions is one of the things that CIL did was set up the development office. Lynn Kidder worked in it and Hal Kirshbaum. I don't know--I'm going to say that it was around the same time we set up the grants office--so it was late in '78 or the beginning of '79. That was really a fundraising office. That was when we began to have a little nicer brochure. Lynn did a lot of that writing.

See, I think they are responsible, too. I mean, I'm giving Judy credit for all these people who came through. I think what would happen was Judy would make contacts with people that she'd turn over to Lynn, and then Lynn would schedule them. Then the whole idea was to get people to sign up to be Friends of CIL, so that they would give money, non-discretionary money--indiscretionary money [chuckling]--non-discretionary so that it could be used as it was needed.

Some of this stuff, like the media stuff because I remember, Channel 4 really got involved. They were always supportive. They could always be called if there was going to be some kind of demonstration at the theater or at the federal building or whatever. They were very supportive.

There was a woman, Valerie, who is African American. I can't remember what her last name was. But she would always do the disability beat. I remember going to a meeting at San Francisco Foundation, I think it was. She was there, and I had to go representing CIL because something happened. Judy was out of town and she couldn't go or something. I remember just feeling like I can't possibly do this as a person that didn't have a disability. It was one of the few times, really, in the whole time that I worked there that I ever represented CIL. I mean, generally speaking, it was always a person with a disability who would be the spokesperson.

What was your question? I got completely off.

Bonney: No, you didn't. We're talking about civil rights and your consciousness.

McMuldren: Yes. There was not a day that it happened.

Impetus for the Movement in Berkeley

Bonney: Why do you think these particular people were the ones that got the movement going?

McMuldren: Who knows? Maybe somebody else would have done it if they hadn't. I kind of had the belief that somebody else would have written Beethoven if Beethoven hadn't written it [chuckling]. I think it would have happened. It's kind of like the conversation we were having when you first came in. I think part of it was the times, that there was just such an awareness of civil rights everywhere in the country and the Vietnam war. It was just good timing for people with disabilities to begin to assert themselves.

I think there was the element of this group of people that was a strong core group that had grown up together in this totally inaccessible New York environment, so I think that was a factor. But I think some of the people who were attracted to CIL were people who--I'm thinking of people in deaf services, for example--were pretty political before they got there. Dick Santos. He was very political. I don't know how much his disability had to do with it.

Then it was, like, once somebody said or once CIL started, some of these really political people who happened to have disabilities were then drawn into it.

Then there were radical people who didn't have disabilities, who got attracted to CIL because it was such a radical environment. Then, I think, they taught--I mean, they kind of taught--people how to go about doing the work.

Oh, and the other thing I want to say, too--the other thing about that community--I'm not going to be able to tell you this without crying. I had contact with so many people who really came there as a last resort and were really giving up. Basically came out to Berkeley and just thought--I mean, I remember two specific people vividly--I mean, they were truly suicidal when they arrived. It was just, "I don't care if I live or die."

[Crying softly] They just completely transformed. Really, to begin to use their minds again and to decide that there were things they could do and they wanted to do. I mean, one person became very politicized and became a very radical person. The other one just basically began to have a normal life and got into a relationship. This was somebody who

thought they would never have a relationship after their accident.

I mean, that was what really kept me there and made me just so--I don't know. It just changed my life forever to be around that and to be a part of that with people who could create that community. It was just so great. To be in Berkeley at that time when literally a person with a disability could go in a store and be irate because they were treated rudely [chuckling]. I mean, it was like WOW! This is progress. Not only did you absolutely expect to be able to get in, but you expected to be treated like any other patron and accommodated.

In the rest of the world, it's not particularly like that. I mean, it's still not particularly like that here in Tucson. Tucson is another place where a lot of people with disabilities live because, you know, moderate weather. I think there are a lot of places in the country like that.

But I don't know what made it so magical. I just think it was the time and maybe because it was Berkeley. [chuckling] I don't know, but it was. It was magic. It was just amazing.

Bonney: When did you leave CIL?

McMuldren: In the beginning of 1980. I think it was maybe in April of 1980. So I did the grants office for maybe about a year, and then I left. Again, my husband was getting out of graduate school. We had actually planned to leave that spring of 1980. He didn't get finished. You know, Ph.D. kind of thing. He didn't have his work done.

But I had sort of set in my mind that I was leaving that spring. It was, like, I just couldn't stay. I was very, very burned out. It was a burn-out environment. I think I portrayed that! I just needed to leave. So I did some grant writing with CIL after I was off the staff. I did a year-end report, and I wrote a continuation grant or two. I still kind of worked with them a little bit.

When I left, we were still in the portable building. We hadn't redone the back room. I mean, I couldn't believe it when I went back. They had remodeled the back room, which was shortly after that. It was the beginning of the eighties. I haven't even kept up with all the different directors and stuff.

Michael Winter as an Intern at CIL

McMuldren: But one of the people that I also haven't talked about is Michael Winter. When he came to Berkeley, I supervised him. He came to Berkeley as a master's internship. The joke of it was I was one of the only people who had a higher-level degree, so I was assigned to supervise him [chuckling]. God, I tried so hard to supervise him. He was not to be supervised. I mean, he wanted no part of it! Me and Jeff Moyer, because Jeff had a master's. So together we were supposed to supervise Michael.

Well, Michael was just, I mean, he was doing four thousand things. He was just totally into the community and into tons of activities. I remember this one time I was trying to get him to plan what he was going to do [laughing]. I remember even Jeff ganged up on me. It was, like, "No! We're not doin' this! This is not happening!"

Anyway, so, yes, I worked with Michael a lot when he first came to Berkeley. See, I think he might have been funded through school because I remember he was just kind of a free-wheeling advocate [chuckling]. I can't remember what we gave him as an assignment.

Bonney: I was going to ask what he did.

McMuldren: I know. I'm trying to remember what he did. I just remember him being there all the time and being involved in all these different things that were happening. What did we have him do? You know, I'm having this memory of him being in attendant referral. I think what we might have done is we might have had him rotate through core services.

Bonney: That would make sense.

McMuldren: Yes. That actually does make sense. Maybe we did something that made sense! [laughing] But, no, he organized the protest about the movie, *Coming Home*. That one I remember. He was pretty radical. He was definitely into organizing.

Bonney: This was before he went to Hawaii.

McMuldren: Oh, he did?

Bonney: Yes.

McMuldren: See, I don't even know that.

- Bonney: He ran an ILC in Hawaii.
- McMuldren: Well, he came back and ran CIL, right?
- Bonney: Yes.
- McMuldren: I didn't know he went to Hawaii.

Leaving CIL and Work in Santa Barbara and Arizona, 1980

- Bonney: Well, Bette, what happened to you after you left Berkeley? Where did you go?
- McMuldren: I went to Santa Barbara. I worked in a community agency. I took this job which was to run a housing program again. It was a shared housing program. It was supposed to be a program for people with disabilities and people who were older. The idea was to match people up in housing situations where some people did jobs for others in exchange for housing. Sometimes it was just a shared kind of household.

I frankly have to say I was pretty burned out. I went to Santa Barbara. The first thing I did was get involved with the independent living center there. There was a center on deafness that really was--I think it was run by one volunteer or something. I worked with him. I wrote a grant with him when I first moved there. Like I say, I got involved with the independent living program, but I really didn't want to do that. I was pretty burned out, and I couldn't see a way of doing it without it being just overwhelming.

Anyway, so I got this job in this little community agency, and I ran this little program. I did that for, I don't know, two or three years. One of the fantasies in Berkeley had always been that we were going to have a restaurant. So what I did was I left services in Santa Barbara and I worked for a restaurant for a couple of years. I actually learned how to manage a restaurant. I did that.

Actually, that was my transition when I moved to Phoenix. I worked for this restaurant. It was a Good Earth Restaurant. At the same time, my husband was doing a post-doc in Santa Barbara. Again, we were there for a limited time while he was doing this post-doc work. I think we were there for three or four years.

Then he got a job at Arizona State [University], and I transferred with the restaurant. But then I quickly left. As soon as I got to Arizona, I went back into services and I went to work for the state. I worked for the Division of Developmental Disabilities first. My job was to identify people in the caseload who could be referred for vocational services [chuckling]. That program is still around. They had had somebody in the program who had been identifying people, but she had only been there for less than a year. So I really kind of got to take that and really make it a program. It was very interesting because it was very much of a liaison between the Developmental Disabilities Division and vocational rehab.

I think the other reality for me was it felt like it was one place that I could work that I didn't feel that somehow it ought to be a job that a disabled person--you know, that somehow I was in a job I shouldn't be in? Working with people with developmental disabilities was a whole new thing for me. Yet, there were so many of the same issues in terms of trying to get people involved in their own plans.

In Arizona at the time they had just closed--in fact, there's still an institution in Arizona--but they had just closed a big one in Phoenix. People were thinking more about getting people to work. So anyway, I got to do that for a couple of years. Then I actually worked at voc rehab, as a rehab counselor. Again, it was still with the same population. I worked with people who had developmental disabilities primarily. Did a lot of supported employment with enclaves and things like that in Phoenix.

Then, after that, I started to do training. I went into the central office of the rehab agency in Phoenix as a trainer. They had a department for training. We did the conferences and set up workshops in training for the rehab counselors, for the voc rehab counselors, and did a core training for new counselors coming in and just kind of all the aspects of being rehab counselor.

Actually--oh, oh, and this makes me think of CIL--because one of the other things I did when I was at CIL was I set up new employee orientation because there were so many employees and there was so much turnover. Anyway, that was one of the things that I did at RSA [Rehabilitation Services Administration]. It was just a flashback for me: setting up the schedule where people for several days were in this room listening to all these different people come in. I'd always have people come in from the independent living program to talk about what was independent living.

I don't know what it is in California, but in Arizona there are also independent living counselors in the agency, in the state agency. They worked together a lot with the independent living programs on home modifications and stuff like that, where they do joint funding.

Anyway, so I did that. Anyway, then, as we come full circle, I got this call one day when I was doing training in Arizona. One of the things I had done, when I did one of the conferences, I had invited Judy out to do a workshop. Anyway, so then I got this call from Don Galvin, who is my boss now. He said that Judy had given him my name [chuckling]. Like I say, here we are, twenty years later, and Judy had given him my name, and he said, "I need a director of training at CARF. Judy highly recommends you. Would you be interested in talking with me? Would you be interested in interviewing?"

Anyway, so I had never really known that much about CARF but as a rehab counselor had gotten to know kind of what it was about. Then, in my last year that I had worked as rehab counselor, no, actually, I guess it was when I worked in central office.

What happened in Arizona was they decided that all vocational services should be funded by rehab services. So all the things that developmental disabilities had been funding--the idea was to re-evaluate everybody--and if what they needed was a psycho-social program, that DD should fund them, and if what they needed was job training, they should go to voc rehab. If they wanted to work, they should go to voc rehab no matter what level of work it was going to be. The idea was to meet with the individual preferences of people.

Anyway, so I did that. I was in the middle of doing that project, of transferring all those people--it was hundreds of people--over to voc rehab and reassessing everybody. I mean, I wasn't doing the assessments. I was coordinating and getting them all assigned to voc rehab counselors and working with all these providers and stuff.

So I was really not looking for a job.

##

McMuldren: I had learned about CARF in the process of doing this transfer of all the cases that were in the developmental disabilities system, getting all these folks transferred over to voc rehab. All I had ever really heard about CARF previously had been that it was kind of like this paperwork process, and they would send

these people in to review the program but they would look at files and they'd be picky about whether the psych eval[uation] was three years old. It was just, like, [making a sound halfway between clearing her throat and a growl]. Just a waste of time, not looking at the quality of the services.

So during this project I had heard about CARF, and then I got this call from Don. So I went. I had always kind of wanted to live in Tucson. I had always liked Tucson so much better than Phoenix. In the meantime, I had gotten a divorce, and I was kind of recovering from the divorce. So I was really happy to have the option of getting out of Phoenix without having to strike out on my own and go someplace by myself. Here it was, you know, this job.

Frankly, I think I could have walked in there and said anything. It's kind of like what I was talking about with the grants. Judy had told Don, "Hire Bette," and he was hiring me. My supervisor now, we have a similar kind of situation, where there's a vice president and president, instead of a deputy director and director--and a woman and a man--and the woman, who is the vice president, is my direct supervisor. Now we're very good friends, and we work very closely together. She said, "Well, I hired you because Don insisted we were hiring you, but I didn't think you knew anything about this. I didn't think we should hire you!"

It has turned out to just be a really wonderful job for me, and it has just been great. It has been a really fun, fun place--fun job--good job, and I get to do the training programs for people who go out and survey organizations. Frankly, CARF has really very much changed from that paper process. It's very much more oriented toward observation of programs and talking with people and interviewing people who are receiving services. You know, much more consumer focus than it was when it started. It started in the sixties. I mean, it has been around a long time.

Then I do national conferences and regional trainings and stuff like that, so it has just been a fun, fun job for me. I thank Judy for it. [laughter]

Bonney: The relationship never ends, right?

McMuldren: Yes, big changes and--

Final Thoughts

Bonney: Well, Bette, is there anything else you'd like to say that I haven't asked you about?

McMuldren: I was trying to remember if there was anything else I didn't hit. I'm wondering if--maybe we could take a break and eat and then I can look through my paperwork and my pictures and just think if there are other things I want to talk to you about.

Bonney: Sure.

[tape interruption]

Bonney: Okay, do you have any last thoughts, Bette, that you'd like to leave with us?

McMuldren: I'm thinking there are a lot of people that I never mentioned who were just important to me in those days. As I talked, I had so many more memories come up. I just feel appreciative of the opportunity to get to talk about those days in Berkeley and those people that I knew at that time and worked with and some that I'm still in touch with. I don't know. It was a gift in my life to be a part of that community and to be--I think that I learned from the experience of being at CIL. I definitely was politicized about disability issues, but also I think I learned as a person without a disability, participating there, I very much learned what it is to be disempowered, and really felt those feelings that people that I was around were experiencing and the overwhelming job that was ahead of trying to really change things. Yet, at the same time, the idea that it was really do-able because we had success. So the feeling that it's a big job but it really can be done, and it is being done. So here we are now, and things have changed a lot, and I'm sure they will continue to.

So anyway, it has been a really fun opportunity to talk with you. I appreciate it.

Bonney: Thank you. Well, it's been a great interview, and we've learned a lot from you.

McMuldren: Good.

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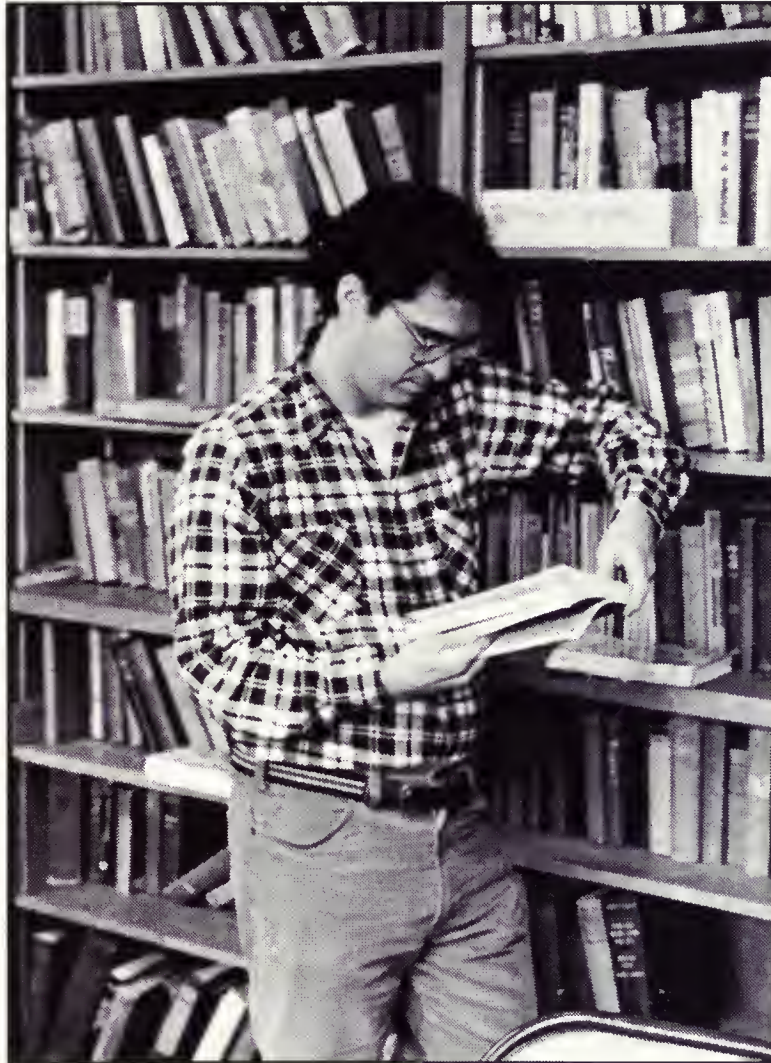
Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME I

Kenneth Stein

PUBLIC INFORMATION COORDINATOR FOR THE CENTER FOR INDEPENDENT LIVING
AND PARTICIPANT/OBSERVER OF THE DISABILITY MOVEMENT

An Interview Conducted by
Jonathan Young
in
1998



Kenneth Stein, circa 1982.

TABLE OF CONTENTS--Ken Stein

INTERVIEW HISTORY	170
BIOGRAPHICAL INFORMATION	171
I	
EARLY YEARS, FIRST JOBS, AND WORK AT THE CENTER FOR INDEPENDENT LIVING [CIL]	174
Childhood, College Years, and Early Jobs in Berkeley, 1947-1974	174
Overview of Work at Center for Independent Living, 1974-1979	176
Impressions of CIL and Its Clientele	180
Extraordinary Growth of the Center and Its Near Collapse	184
Pivotal Moments in the Center for Independent Living's History	191
CIL's Demographics: Race, Gender, Sexual Identity, and Disability	193
The Center for Independent Living and Local Politics	199
II	
VOLUNTEER WORK, PERSONAL INTERESTS, MARRIAGE AND FAMILY, AND DREDF	202
Comparisons of the Center for Independent Living and the Disability Rights Education and Defense Fund	202
Founding of the Berkeley Historical Society, 1978	204
Chairman of the 504 Celebration, 1997	205
Photography Work	207
Marriage and Family, 1986	209
Work on ADA Hotline at DREDF since 1993	209
Addendum	210

INTERVIEW HISTORY--Kenneth Stein

Kenneth E. Stein has worked in the disability field since 1972 when he became a reader for a student with a visual disability at the University of California at Berkeley. He has firsthand knowledge of the Center for Independent Living, the Disability Law Resource Center, and the Disability Rights Education and Defense Fund where, currently, he directs the ADA Hotline.

At the Center for Independent Living from 1974 to 1979, Mr. Stein was the first public information coordinator, the first librarian, and assistant editor of The Independent, the center's quarterly magazine. During this time he also wrote reports on peer counseling, "Gaps in Services to the Severely Disabled," and co-authored a report to the Metropolitan Transportation Commission on "The Impact of BART on the Physically Disabled." At the Disability Law Resource Center, Mr. Stein reported for and edited their national newsletter and compiled a directory of social services in Berkeley and Oakland.

He supported the 504 sit-in by demonstrating outside the Federal Building in San Francisco, and through the years he has collected an extensive library of documents and original audio and videotapes of news broadcasts and events about the independent living movement. He has about seven hours of audiotapes of newscasts of the 504 sit-in from TV and radio. These tapes are very rare since there was a media strike in effect during the 504 sit-in time period and almost all news reports were discarded by stations after being shown on TV. In 1997, Ken Stein was chair of the 504 celebration which commemorated the twentieth anniversary of the sit-in. His intense interest in history and in preserving the historical record is evident not only in his personal archive of materials relating to the disability movement but also in his long service to the Berkeley Historical Society and the City of Berkeley Landmarks Preservation Commission.

Mr. Stein has chemical sensitivities to smoke and to scented products, and he limited his activities for many years to avoid potentially dangerous environments. He reflects on his environmental sensitivities and his relationship to the disability community in an addendum to his interview.

The interviewer, Jonathan Young, conducted two interview sessions on January 16 and January 21, 1998, with Ken Stein. Sharon Bonney edited the interview and gave it to Mr. Stein, who made moderate corrections and provided additional information in some areas. On December 10, 1998, a forty-five minute videotape was recorded with Mr. Stein and Ms. Bonney. The videotape and audiotapes are available for viewing and listening at the Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sharon Bonney
Editor

December 16, 1998
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

KENNETH E. STEIN

EDUCATION

University of California, Berkeley, California, Graduate Department, Sociology

Recipient, National Institute of Mental Health Traineeship, Training Program in Social Structure and Personality, University of California Berkeley/Graduate Division

University of Illinois, Champaign-Urbana, B.A. in Sociology, Psychology, English, magna cum laude

PROFESSIONAL EXPERIENCE

**Manager, ADA Technical Assistance Unit / ADA Technical Assistance Specialist,
Disability Rights Education and Defense Fund (DREDF), Berkeley (1993-present)**

Manager of ADA Technical Assistance Unit. Provides ADA Technical Assistance, Information and Referral on national Department of Justice-funded "800 Hotline," for national disability law policy center dedicated to furthering the civil rights of people with disabilities. Oversees overall operation of ADA Technical Assistance Unit. Also, organized & maintains ADA resource library

Technical Assistance/Communications Specialist, Accessible Environments, Inc., Berkeley, California (1993)

Provided ADA, §504 & Title 24 Technical Assistance, Technical Writing and Communications services to full service consulting & architectural firm specializing in disability related laws, regulations, and barrier free design.

Communications/Dissemination Specialist, Pacific Disability and Business Technical Assistance Center (DBTAC), Berkeley Planning Associates, Oakland, California (1991-1993)

Responsible for designing and disseminating program information for Federal Region IX Americans with Disabilities Act (ADA) technical assistance center. Provided "800 Hotline" ADA technical assistance. Planned and coordinated workshops & conferences. Responsible for the development and production of Region IX ADA informational and technical materials including project newsletter, brochures, & resource guides. Established on-site technical assistance library.

Dissemination Specialist, Berkeley Planning Associates, Oakland, California (1991-1993)

Dissemination and Technical Assistance Team Leader for Region IX Rehabilitation Information Network. Planned and coordinated workshops; designed and produced newsletter for project providing technical assistance and information support to service providers in the areas of supported employment and rehab services for elderly persons.

Communication Resources Specialist/Public Information Coordinator, Access California, City of Oakland Office of Community Development, Oakland, California (1988-1991)

Duties included writing, editing and production of statewide newsletter, publication design, layout, and production supervision, information and referral, and administrative support for municipal disability access program.

Writer and Editor, Berkeley/Oakland Support Services, Oakland, California (1989)

Drafted Annual Program Report for social services agency which provides support services to people who are homeless.

Professional Photographer (1979-1989)

Experience includes extensive local, regional, and national press, magazines, organizational brochures, newsletters, annual reports, municipal reports, textbooks, and catalogues.

Field Representative to School Board President, Berkeley Unified School District, Berkeley, California (1983-1986)

Technical Aide and Office Manager, Access California, City of Oakland Office of Community Development, Oakland, California (1985-1986)

Edited a guide to the physical accessibility of facilities in Oakland and Berkeley.

Support Services Assistant, California State Department of Rehabilitation, Oakland, California (1983-1984)

Provided support services to blind vocational rehabilitation counselor.

Editor/Researcher, Disability Rights Education Defense Fund, Berkeley, California (1980-1982)

Edited national newsletter; researched and developed a resource guide on employing disabled individuals, targeted to employers and rehabilitation specialists.

Public Information Coordinator and Researcher, Center for Independent Living, Berkeley, California (1974-1979)

Compiled a comprehensive directory of social services available in Berkeley and Oakland; reported for and edited a national newsletter for the Disability Law Resource Center; assistant editor of CIL's national quarterly magazine. Conducted research on the efficacy of CIL's peer counseling program, analyzed gaps in social services to persons with disabilities, and co-authored report to the regional Metropolitan Transportation Commission on the impact of rapid transit services on physically disabled persons.

Staff Member, Bonita House, Berkeley, California (1972-1974)

One of four original staff members responsible for overall operation of psychiatric residential care facility

PUBLICATIONS

Americans with Disabilities Act "Pacific Center Update," Berkeley Planning Associates, 1992-1993 (Editor/Writer/Production Supervisor).

Access California Bulletin, statewide disability access newsletter, City of Oakland, 1988-1991 (Editor/Writer/Production Supervisor).

Berkeley/Oakland Support Services Annual Report, 1989-1990 (Editor/Writer).

Bay Area Resource Guide for Public and Private Employers, Rehabilitation Professionals and Vocational Specialists, DREDF/Employment Law Center, 1983 (Author/Researcher).

Let Your Fingers Do the Walking: An Access Guide to the Oakland/Berkeley Area, City of Oakland, 1981/1986 (Editor/Photographer).

Community Resource Guide: A Comprehensive Classified Directory of Social Services in the Berkeley/Oakland Area, CIL, 1979 (Author/Editor).

Access, National disability rights newsletter, Disability Law Resource Center, Berkeley, 1978-79 (Editor/Writer).

"Peer Counseling at the Center for Independent Living -- A Detailed Analysis of CIL's Research and Demonstration Project," 1979 (Author/Researcher).

"Architectural and Historical Cultural Resources Survey Report," West Berkeley Industrial Park/Berkeley Redevelopment Agency, City of Berkeley, 1978 (Research Associate).

An 1878 Residential and Classified Directory of West Berkeley, Otherwise Known as Ocean View, 1978 (Author/Publisher).

"A Bird's-Eye View of Berkeley, 1891" Historical Map, 1977/1983 (Publisher/Distributor).

"Gaps in Services to the Severely Disabled," in CIL Rehab System for the Severely Disabled, 1976 (Author/Researcher).

The Independent, National Quarterly Magazine, CIL, 1974-77 (Assistant Editor).

"The Impact of BART on the Physically Disabled: A Pilot Study," Metropolitan Transit Commission, 1975 (Co-Author/Researcher).

Urban Institute Comprehensive Needs Study of Persons with Severe Disabilities, Urban Institute, 1974 (Research Assistant/Writer).

OTHER PROFESSIONAL ACCOMPLISHMENTS

Honorary Committee/Guest Panelist, Center for Independent Living 25th Anniversary Program, 1997.

Organizer, Steering Committee Chair, 504 Sit-In 20th Anniversary Celebration Committee, 1996-97

Participant, The Campaign to Prevent Handgun Violence Against Kids, California Wellness Foundation, 1995-97.

Commissioner, City of Berkeley Human Welfare and Community Action Commission, 1991-92.

Planning Committee, Independent Living: Preparing for the 21st Century Conference, Oakland, California, October 1991.

Commissioner/Chair, City of Berkeley Landmarks Preservation Commission, 1983-89.

Authored and successfully advocated for the City of Berkeley's Non-Residential Demolition Ordinance. Co-Authored the City's Design Review Ordinance and Landmarks Preservation Ordinance amendments.

Convener of Homeless Workshop, BCA Platform Convention, 1988.

Facilitator, City of Berkeley General Plan Meeting, 1988.

Planner/Speaker, Town Meeting on Homelessness, 1987.

Editor/Reporter/Photographer, Grassroots Newspaper Collective, 1976-1986.

Member, City of Berkeley Downtown Plan Committee, 1986-1988.

Co-Founder, Past President, Board Member, Berkeley Historical Society, 1979-present.

INTERVIEW WITH KEN STEIN

I EARLY YEARS, FIRST JOBS, AND WORK AT THE CENTER FOR INDEPENDENT LIVING [CIL]

[Interview 1: January 16, 1998] ##¹

Childhood, College Years, and Early Jobs in Berkeley, 1947-1974

Young: We'd like to begin by going over some basic personal history. I'd like to ask you when you were born and then if you could mention briefly your educational background and, as well, where you were born.

Stein: Yes. My name is Ken Stein, Kenneth Erwin Stein. I'm fifty years old. I was born in Chicago, Illinois, on December 8th, 1947.

Young: Did you grow up in Chicago? Went through high school?

Stein: I grew up in Chicago. When I was nine years old--eight or nine years old--my family moved out to Skokie, Illinois, from Chicago, where I lived until I started attending University of Illinois. I still officially lived in Skokie till I graduated college, but, you know, I went to University of Illinois in Champaign-Urbana from 1965 to '69. And I came out to Berkeley in 1969.

Young: What brought you to Berkeley?

Stein: I had graduated from University of Illinois and took a year off, and I came out here to just kind of hang out. I really didn't know the difference between San Francisco and Berkeley. It was sort of on the heels of the whole hippie thing. So I came out and spent a year out here and played recorder on the Sproul Hall steps and just kind of hung out.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

It was the year after that I went to graduate school here for one year in sociology. I don't think I finished any of my classes that year (and ended up with incompletes in all of them). I wasn't happy. It had a very good reputation as a school. I came out with a four-year traineeship in social structure and personality and sociology, but it was all very theoretical and I was a very here-and-now kind of person. I couldn't relate.

During that year, I had become involved with the Stiles Hall Project, which was a volunteer program going up to Napa State Mental Hospital on the adolescent ward, where we visited the kids. I don't remember if it was once or twice a week. And from that experience, I began working--the next year, when I was not in school anymore--I dropped out of the graduate program and began working at Bonita House, a psychiatric halfway house, where I lived and worked for two years. It was Berkeley's first psychiatric halfway house. And it was sort of a trend-setting thing those days. There were four of us who worked there. Four staff people were responsible for everything. I wasn't the director; I was one of the staffers. I worked there for two years.

Do you want me to go on a little more about how I got into the disability--

Young: CIL [Center for Independent Living]. I mean, it seems like that was a good transition, working with mental health issues.

Stein: Well, it wasn't that organized a thought process. I'll explain how that happened. I worked at Bonita House for two years, and a good friend of mine was killed. He was murdered by the predecessors of what in the following years would come to be known as the Zebra killers. I was pretty devastated by that experience and I think was in no condition to have to take care of anybody else. I really needed time off, for myself. I was sort of burned out at Bonita House at the time anyway, I think, because it was--the way things worked then, we were live-in staff. Now they don't do that anymore, but we were live-in, so it was pretty much even though you had time when you were on duty or you were off duty, you were really on twenty-four hours a day, and it was a lot of responsibility. I was only--let's see what year that was--1972 to '74, and I was born in '47, so whatever that--

Young: Twenty-five years?

Stein: --pencils up to, that's how old I was. So I left Bonita House after that. I just needed some personal time to deal with a bad, hard experience.

I was on unemployment, and in those days--I guess still now--when you're on unemployment, you see an employment counselor and have to try to get jobs. My employment counselor asked me what my criteria was for work, and I said my primary criteria for work is that I want to be able to sleep till noon. He was a blind rehab counselor, and he said, "Well, the only thing I know of where you can do that is reading to blind students at UC Berkeley." I said, "Great."

So I became a reader through the Physically Disabled Students' Program, PDSP. I was a reader for a student named Patty Finnegan, and I stuck with her for, I think, for a few years, as my recollection, till she graduated. I was her reader. I did a lot of reading for her, taping textbooks and different things. She graduated, and that job ended.

I was, I think--I was still unemployed or marginally employed, not doing much of anything, and I happened to get a call one day because my name had been transferred over somehow from PDSP to the Center for Independent Living. I didn't know who it was who was calling me or what they were calling about, what it was. They were saying a lot of initials, a lot of names: CIL, Urban Institute. I didn't know what it was, but it was a job to assist a person with a disability in a project. I said, "Okay."

So I went over there. CIL was on University Avenue in those days.

Overview of Work at Center for Independent Living, 1974-1979

Young: Had you heard of CIL before that call?

Stein: No, I didn't.

[tape interruption]

Stein: I walked in and there were a bunch of pictures on the walls of people with disabilities doing different things. One or all of them--I don't remember--was scenes at a BART station. There was some guy with a head stick there, who looked really weird, and I said, "Just my luck. I'll get that guy." Of course, I did get that guy. That was Hale Zukas, who I ended up working with very closely for a number of years at CIL.

At the time, CIL was in a project called the Urban Institute Comprehensive Needs Project for Persons with Special--let me get

the name of it exactly. Urban Institute Comprehensive Needs Study of Persons with Disabilities. Hale Zukas is someone who was one of the founders of CIL and who has stayed with the independent living movement for all these years. He's over at WID [World Institute on Disability] now.

At the time, there were no computers. Hale used a Selectric typewriter. He has pretty severe cerebral palsy. He can't communicate well, orally, verbally. He's not that understandable. He types with a head stick and moves his wheelchair with a head stick. And so in those days, the way he would work is that he would type out in sort of abbreviated code the words onto the typewriter, and then I would type it out long hand--or type out all the words to do his report. He was one of the people who had one or more of the pieces of this report, which a number of people--maybe eight or ten people had been hired--each to write a piece of this for the Urban Institute.

After that, what happened was that the project ended or the time period for these people to work ended. But a number of the reports weren't really finished, so Ed Roberts asked me if I would work on finishing up some of those reports. Some of them really had to be done from scratch. I don't know how he knew I was a writer, if he just asked if I'd be interested. Well, I'll get into that later about the kind of guy Ed was and his management style because it all ties into that.

So I ended up--what I'm doing now, by the way, is giving, like, a quick overview sketch of how I got involved at CIL. So I began writing, doing writing and editing and doing other reports at CIL. I stayed friends with Hale. I can't remember my work relationship with him because I continued to work with Hale, but I was also doing a lot of things much more independent of Hale: writing, editing. I gradually worked my way into--I was their librarian, I was the first--let me get all my different titles [looking at papers].

I was CIL's first public information coordinator. I did a lot of research, a lot of writing. I was their first librarian. What I have is--I'll read it from my résumé, a little paragraph. In later years for them, I worked at DLRC across the street from CIL. That stands for Disability Law Resource Center, where I compiled a real comprehensive directory of social services in Berkeley and Oakland. I reported for and edited a national newsletter, which was the access newsletter for DLRC. That was in later years, after DLRC got started.

Earlier than that, I was the assistant editor of The Independent, which is CIL's quarterly magazine. I did a report

for CIL, a major report on peer counseling. I did a service gap report--"Gaps in Services to the Severely Disabled"--I co-authored a report to the regional Metropolitan Transportation Commission on the impact of BART on people with disabilities. I co-authored that with Hale and Eric Dibner. I did research and helped write a speech for Phil Draper that I think he presented to Congress on the need for seat belt legislation. So I did quite a bit of work over the years for CIL. I worked at CIL from 1974 to 1979.

Young: Which of your projects stood out to you as the most important? Or they demanded most of your attention?

Stein: Before I get to that question, I should say that I worked at CIL from '74 to '79, and then worked at DLRC, DREDF [Disability Rights Education and Defense Fund], from 1980 to '82. So it was a pretty straight run from '74 to '82, even though there were time period gaps. In later years, '80 to '82, I was working as an individual contractor on special projects. So that is basically the sort of quick overview sketch of my involvement with CIL and how I got into it.

Young: What were your first impressions of CIL?

Stein: I missed the question you asked just a moment ago.

Young: Do you want to go back to it now?

Stein: I'll go back to that, yes.

Young: What stands out to you as the most important thing that you did or the thing with the most significant responsibility?

Stein: At CIL?

Young: Yes.

Stein: I don't know. I guess--well, one thing, I think, I did that was really important--

Young: Maybe it seems like all of them kind of held equal weight and not one project was--

Stein: Well, in terms of--I mean, historically, I think, what's important is--one particular thing I did was really good was contacting ABC [American Broadcasting Corporation] News, because they had a weekend--they had their weekend news show, and they said, "Oh, if you can think of a story that's interesting..." So I contacted them about CIL. I rediscovered this tape, like, five years ago,

and it was a surprise to hear the tape again. They ended up coming out to do a story, and it was--Ted Koppel was the narrator. He was the anchor then at ABC News. He said, "Chances are, you've never heard of the Center for Independent Living or the"--I think he called it the handicapped rights movement, something like that. No, he said, "the disabled liberation movement. Neither had we. But Ken Stein of Berkeley, California, wrote us" and blah-blah-blah. So I didn't know Ted Koppel had ever uttered my name, so that was interesting to hear. [Tape available in the Disabled Persons' Independence Movement Project Archives.]

Young: You still have that tape.

Stein: Yes, I have the tape. But what's significant about it, it was the very first national coverage of CIL, and it undoubtedly had a profound impact in terms of letting people know all over the country about CIL as an organization and independent living as a movement. People really began flocking to CIL. Not just from that. There were other avenues. But this was the very first national coverage of CIL in mainstream America. And the kind of impacts something like this have can be seen by--

There's a book of thumbnail sketches of people with disabilities, important people with disabilities around the country. There was a--Russ Cooper Dowda is--actually, it's in Ed Roberts' biography. It starts out talking about how Russ Cooper Dowda was laying in her hospital bed, about to be transferred to a nursing home, essentially for the rest of her life, and she was watching--it turned out, when I called her and talked to her about it--it wasn't this. It was a *60 Minutes* report about Ed. She saw it, and the next morning she said, "Hell, no, there's no way I'm going to a nursing home." She came out here. So, like, it really changed her life.

So the kinds of impacts these reports have were very important. So I think that's one good thing. One never knows what the real important impacts are, but, I mean, all the reports are important. The whole issue of the peer counseling report was very important. The Independent was a national, quarterly newsletter that went out to a lot of people as a magazine.

Young: I was reading through some of those. I enjoyed those.

Stein: Yes, and they were good. The "Gaps in Services" was a very, I think, historically significant report in the sense that this was done in 1976, and it was a very comprehensive look--although based on anecdotal material--but it was very thorough in terms of what are the gaps in services that people with disabilities in all different areas--from Medicare and Medi-Cal, employment, all kinds

of things. And it would be real interesting now because it was just the year before 504, and it was pre-ADA, to compare how far we've come and how far haven't we come. So historically I think that's of some importance.

Probably the most--something that I feel is a most important contribution to disability rights history was at the time I was at CIL, but it wasn't done officially through CIL, was during the 504 demonstrations. And what I did at that time--I've always liked history and had a sense of history. It became, it was real clear early on that that demonstration--that this was a really historic thing happening. And so what I did, the very first day, I taped a lot of the TV coverage, an awful lot, of all the different--I don't know if I got noon news that day--probably not, because that's when it was happening. But the five o'clock, the six o'clock, the ten o'clock, the eleven o'clock news. And also network coverage.

The second day I didn't do that much recording, but from the third day on to the end of the demonstration I taped all of the--I had two tape recorders going and a little pocket radio-TV that I used and also my regular TV. And pretty much got I'd say 90 percent, 95 percent of all the TV coverage at that demonstration.

Young: That's outstanding. Do you still have these materials?

Stein: Yes, I do. It's about seven hours, six or seven hours of recordings. Why it's so important is that there was a strike on at the time. The TV stations did not save any of this stuff, so this is really a tremendous record. That material was used as the basis for the 504 celebration committee's audiotape (the radio documentary), and also a lot of that footage, audio footage, was used for the TV documentary, both of which were produced by the 504 twentieth anniversary celebration committee for the 504 anniversary event. A lot of it was also used by National Public Radio in "Beyond Affliction," a recent NPR documentary on disability rights. So in terms of something I'm real happy that I did, that really stands out to me.

Impressions of CIL and Its Clientele

Young: I started to ask you what your impressions were of CIL when you first walked in the door and began as an employee. What did you think about the organization?

Stein: I was one of the speakers at CIL's twenty-fifth anniversary dinner on October 30th, 1997. So I talked about my sense of the importance of the early days. You can have a copy of this if you want to attach it. [See Appendix] What I talk about in this speech is certainly one side of it. What I said there was that people often talk about CIL as an "it" ("it" in quotes), forgetting about the many people who've made the organization tick and of the interplay between those people, and the success of the movement.

I also talk about--I say what's clear to me is that [reading]: "the success of the independent living, disability rights movement is not so much a history of heroes and lone wolves as it is a history of interdependence, community and connectedness." And in my speech I talk about, I expand on that, which I don't need to do here because you can have it.

But as far as what it was like, and impressions. What Mary Lester said when I talked to her about doing--when I was going to be giving this talk--she said that, quote [reading], "I remember the enthusiasm and energy for challenging the system, knowing that we were all on the verge of something big, undefined, unknown but very exciting." What I said at the CIL talk is that for a variety of reasons CIL's early staff members were people who could all identify mightily with the idea of independent living. So it started with that as a context.

One time years ago, Mary Lester had said to me that we were all a bunch of flotsam and jetsam there. And that was my original draft of the speech. I took that approach and I talked to Kitty [Cone], and she said, "Oh, no! You can't say we're flotsam and jetsam. You have to say how we were all"--what--

Young: What did she mean by that?

Stein: I'll tell you in a sec. But [looking through papers]--what Kitty had said was, You have to talk about how CIL attracted people who were enthusiastic and knowledgeable and brilliant. But what Mary meant by the flotsam and jetsam comment was that basically we were--what Mary was talking about in regard to challenging the system, we all came out of the sixties. It was the tail-end of the sixties. And I think when we talk about "the sixties," we're really talking about the seventies, but in my life--and I think maybe in the life of the country--the sixties was really the seventies in terms of the political stuff that happened. There might have been some cutting-edge things and turning points in the sixties, but I think that the ripple down through the rest of the country to my life and many lives was really the seventies, so I'm always surprised when they talk about the sixties. Because the

sixties, I think, people were pretty much the fifties. But anyway--

Young: What did CIL look like?

Stein: Wait. I didn't answer your question about flotsam and jetsam. I don't know. It's like--I'm sorry I don't have the words to describe it well. We were just people. It wasn't, like, a bunch of leadership. The leadership was, I mean, Ed was there. But it was, like, we were just folks.

Young: Ordinary folks doing great things.

Stein: Ordinary folks--well, in retrospect it might have been really good. But at the time it was kind of a funky--I'd say it was a real kind of funky place. As far as what it looked like, it was in an older office building. CIL operated two floors. The second floor, the higher one--it wasn't the second--I think it was the third and fourth floors of the building. It was right on top--I can't remember which was which. Mary would remember that. It might have been third and fourth, but it was--the top story of CIL was the Urban Institute Comprehensive Needs Study, and below that was all the other services of CIL, I think. I found out recently there was wheelchair repair back then, as well. I didn't know that had come in so early.

Young: Did CIL have good equipment, or was it struggling to get materials for the office?

Stein: I don't remember. You know, the thing about it--I'm sorry, I lost my thought. One thing I want to say is that I was not a leader at CIL. I wasn't management. I was just somebody who was working there. I wasn't a key player at the time. I think because I was around in the early days, there's some importance in talking to me, but a lot of the administrative things I wasn't part of or party to. I'm really not aware of them.

Young: Well, one thing as historians and as history the way it used to be written about, only the leaders, and there's really been a revolution in history that--

Stein: I understand that. I give that same speech myself because I'm really active in the Berkeley Historical Society, so I know that.

[cross-talk; inaudible]

Young: --key players, your impressions aren't any less important.

Stein: I understand.

Young: One of the things I'm curious to learn more about is kind of the process of how CIL worked. And one way to think about that is when a client first approached CIL, what happened when they came through the door? Who were they referred to?

Stein: There was an intake process. I know you're asking that. I'm going to answer a different question. One thing that was interesting to me in reading No Pity [No Pity: People with Disabilities Forging a New Civil Rights Movement], Joseph P. Shapiro, Times Books, 1984] a couple of years ago was that it's one thing to live through something, and it's another thing to see historically and in retrospect things you didn't realize at the time. What that had to do with was, for instance, wheelchair repair was something--oh, yeah, there was a wheelchair repair service.

But the importance of that in terms of the new concept of independent living that prior to the concept and the idea of independent living, people with disabilities were just supposed to be in institutions or stayed at home. They weren't out on the street, and so wheelchairs were designed for hospitals. They weren't designed to go on sidewalks; they weren't designed to go any great distances; and so the junky E&J wheelchairs would always break down. And so that's why wheelchair repair was a very, very important thing for independent living.

In the same way, only years later (when I saw a recent documentary on Mobility International, which was founded and is run by Susie Sygall) did I come to understand the importance of BORP, the Berkeley Outreach Recreation Program, later renamed the Bay Area Outreach Recreation Program. BORP was started as a CIL program by Susie Sygall and Diane Schechter. What I came to understand years later was the importance of recreational experiences for building self-esteem, etc., which would then translate over to so many other areas of a person's life.

So it was that kind of thing that was interesting to look back--basically, what would happen is that people would go to an intake counselor. I think that's what you'll hear on the Ted Koppel tape. I'll be happy to get you a copy of that. Where they talk about there's an intake; I mean, it basically runs through an intake process right there on the tape. If somebody, oh, "I just got to town," and Nancy D'Angelo, who is dead now, is on the tape, and she's saying, Okay, well you can get wheelchair repair, you can do this, you can do that, you can do that. They'd be targeted to all these different core services.

Young: How would you describe the clientele that came through the door?

Stein: Disabled, mobility-impaired primarily. It's really changed now. I understand that most of CIL's clients, benefits clients now are psychiatrically disabled. There's been a big change over the years. But at that time, CIL was an organization for people with severe disabilities. Deaf services was not part at the beginning. Blind and disabled was because Don Galloway was there and Jan McEwen, the editor of The Independent, was blind herself, the woman I worked with. But The Independent's masthead said, "A New Voice for the Disabled and Blind."

Young: You wrote this report on gaps in services. Were people who came through the door for the most part able to get what they wanted? Or were there pretty profound gaps that were still not yet fulfilled?

Stein: I don't remember. That's not what I dealt with. And that's certainly not what I recall. Things I do recall of importance--one thing I want to talk about, I think, is Ed Roberts at CIL.

Young: Let's hold that.

Stein: Okay, fine.

Extraordinary Growth of the Center and Its Near Collapse

Young: We'll get to that. I want to talk a little bit about how CIL grew. We have a report from 1975 that there were about twelve staff members, and in 1976 in the In-House monthly it reports something about eighty staff members.

Stein: Right.

Young: That's an extraordinary surge of growth. How did that happen?

Stein: Well, you think you changed the subject, but you didn't. It was Ed Roberts. Ed was somebody who said yes to everything, and they really aggressively went after funding sources. A lot of the funding sources were targeted to specific programs, so they would go after--in a sense, I think, in the early days--probably now--I don't know--but in the early days, they certainly followed the money where there was money, and they also created money.

One very important aspect of this--and this is my anecdotal recollection of the process that happened but in talking to other people, it's other people's sense as well--what happened was Ed was a guy who said yes to everything and developed some very, very

important core services. CIL was an organization that was started by a minority group, that was outside of the mainstream, that had a good sense of what they needed but did not have a good sense about how to economically run an organization, so that when CIL started with three or four people, they were sitting around a living room--I think on Haste Street--I'm not sure what living room they were sitting around; Jan McEwen knows.

They'd say, "Well, who wants to be the bookkeeper?" And Bill McGregor, who I think was an attendant at the time, said, "I'll do that." Well, two years later or three years later, when CIL had grown to a million-dollar agency, Bill McGregor was the bookkeeper and now the accountant. And, you know, he was way over his head.

Young: Didn't have any prior professional experience.

Stein: He was clueless. CIL itself, I think, was clueless in terms of how to run a million-dollar organization.

The other big issue was that you'd get demonstration grants, like perhaps for attendant referral or something else which were key, important programs for the survival of people with disabilities to live independently, and then the money would run out. So they would borrow money from other programs. CIL got a tremendous amount--they got away with murder in terms of what we call "crip priv," crip privilege, where the phone company, PG&E, Krishna Copy, the landlord--well, I guess it wasn't a landlord; they owned the building. But whoever. I mean, the stationery store would let CIL say, "We can't pay now; can we pay next month?" Things that no other organization would get away with.

They would borrow money from A to pay B to cover these programs, and borrow money from other programs. And they got deeper and deeper and deeper into debt doing that. They became \$300,000 or \$400,000 in debt. There was a lot of dissatisfaction on the staff because staff--I mean, it was a joke. You'd have to get to the bank fast so that your check wouldn't bounce. If you got to the bank first, your check wouldn't bounce.

Then it got to the point where staff was having to have brown-out periods of who would volunteer, some people would get paid on time and other people would agree to be paid late. They would get paid later. A lot of dissatisfaction on the staff when you have an organization that is run like that and is in such severe financial trouble as they got into. You've got two choices as administration: either you have to cut staff and deal with the problem and make responsible economic decisions, which you should do anyway; or what you have to do is bring people into the

decision-making process and say, "We've got a problem, folks. How are we going to deal with this?" So people need to feel like they're a part of solutions.

But instead, people weren't told anything, and some people got really mad because, you know, they were on the one hand--I guess it brings up parent-child stuff. You know, we're not being told what's going on, or we're being treated like garbage and we don't have decision-making--and it ended up, I think, in a strike, which happened right after I left.

Young: 1981?

[tape interruption]

Stein: --make sense. I was maybe working doing some piece work over at DLRC, but I was on a contract basis. I don't remember in terms of where my personal history corresponded to the strike--but I knew I was not there. I think Judy [Heumann] was the director at that point. I don't know if Michael Winter was there yet.

Anyway, so I mean that's basically--what happened was that Ed had built this huge, huge structure. The way I always think of it was that Ed had created the scaffolding partly for himself, in terms of career--not that it was intentionally that way--but it was a career thing where he moved out to Department of Rehab [California State Department of Rehabilitation] just at the time when this whole scaffolding collapsed. I mean, he was off the boat and the boat sank, whereas CIL had owned all the property. They could have had a fortune. They owned the building; they owned all where Uncle Ralph's was, that whole block; they owned a parking lot. They had to start selling things and selling things and selling things till they had nothing. They had to sell their building. And eventually--I mean, they owned the whole block there up until Gorman's Furniture, I guess, or that building.

CIL went down to twelve people again. And then it gradually rebuilt on a firmer foundation.

Young: So CIL would get, say, a three-year demonstration grant. And when the money of that grant ran out, rather than close the project--

Stein: They kept the project.

Young: They would keep the project going and then pull money from other places.

Stein: Other places, and then get deeper and deeper--and they ran into hundreds of thousands of dollars of debt that way.

Young: And the only people who ever knew what was going on was--

Stein: Management.

Young: --the main management.

Stein: That's correct. We knew there were problems, and I think we all sort of knew what was happening, but they didn't have--partly, I regard it as a minority issue--they didn't have the expertise to know how to run a million-dollar agency. They didn't get it together to do that, and so in a sense the organization failed--

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Stein: --right at the very time where it was becoming a model for the independent living movement and independent living centers all over the country. The irony there.

But part of it was that Ed didn't say no to stuff. That was his real strong point in a sense, that he could bring out the best in people, people who hadn't had opportunity to do stuff before. A good example of that is Earl McKeever. Earl is dead. He was killed by an attendant--who killed him for a stereo system--which points out some of the problems around attendant referral and the need for higher-paid and better-quality attendant services.

What happened with Earl McKeever is, I think, a very telling story. Earl was a guy who called CIL and wanted to get a job, and his power chair was broken. Ed said to me, "Ken, would you go run down on BART to Hayward and check out this guy and see what he's about?" I went and visited with Earl one afternoon. Earl was a nice guy, who had had probably no background much in anything to do stuff, but he was nice and willing and wanted to work at CIL.

I came back and said to Ed, "He seems like a real nice guy, but I don't know that he has any skills or anything." Ed said, "Well, I'll meet with him." So they set up another interview for him to come into CIL. I'm walking into work one morning, and there's a big truck outside of CIL, a big van, and Earl is unloading a lamp and a desk and a typewriter, and a huge, huge worktable. I said, "Hi, Earl. What's up?" He said, "Ed told me to come in and start work today." I went up and I said, "Uh, Ed. Earl's here, and he thinks he's starting work today." He didn't understand that he was just supposed to come for an interview. I said, "What are you going to do?" He said, "Oh, we'll hire him." And that was that! That's how Earl McKeever got hired at CIL.

But it says a lot about Ed, you know. My recollection of Ed is that he said yes to everything, and he went after stuff. And

went after money. In a sense, he was able to bring out the best in people doing that, and in a sense, I think, it's what sunk the organization, financially, for a while.

Young: You said a couple of things that are a little bit in tension with one another. You talked about the quote from Mary Lester, you know, the energy and being enthusiastic in challenging the system. And on the other hand, there's a sense of the sort of morale problems with the staff and the conflicts over the funding situation. Were those kind of things both going on at the same time? Enthusiasm about the programs but then the anxiety about the financial side?

Stein: Sure. But I don't see them in conflict at all. I see it as all part of the same thing. If people who are not dead to what's going on around them, people who are excited about stuff. And if people are excited about stuff and they're getting shafted, they're going to be angry. So I don't see that as a conflict. I see it as sort of it all makes sense to me! But people really were being treated bad as employees.

Young: Now, with this strike, what happened? Did people come back? Did all the staff that were there come back? You talked about the staff dropping down to--

Stein: Oh, no, the organization got sunk, not because of the strike. I mean, it just went broke. It was two separate things. And I'm not a person to talk about the strike because I wasn't there at that time. But no, independent of the strike, I mean, the \$400,000 debt or \$300,000 debt was what sunk CIL for a while. And they had to be bailed out by I think it was the Department of Rehab. So it was a very bad time.

Young: You've talked about this a little bit. Elaborate on it a bit. How were critical decisions made at CIL? Who was making the decisions?

Stein: You know, I can't give a good answer to that. Twenty years ago if you had asked me, I might have known, but I just don't remember. It's not something that I carried with me as an issue. We did have staff meetings. I remember regular staff meetings.

Young: From what you recall about decisions, about where CIL was going, were people in general agreement about CIL's mission? Or were there some pretty significant disagreements about what CIL should be doing in terms of funding or administrative projects?

- Stein: Again, these are sort of top-level sorts of issues that Mary Lou Breslin would probably be a very good person to talk about that. Joan Leon, Kitty, people who were part of that process.
- Young: During your tenure, Ed Roberts was the executive director, and then Phil Draper.
- Stein: Phil, yes.
- Young: And Judy Heumann was the deputy director.
- Stein: Yes, Judy was deputy director.
- Young: You talked a good bit about Ed. How about Phil and Judy? Were their management styles different?
- Stein: I remember Phil as being, in a sense, laid back, whereas Ed, I think, was more high energy. I worked on a number--some, some projects with Phil. The one I recall was he was giving a speech. It was the state legislature or Congress. He needed a speech written, and I did some research and actually wrote that piece because Phil had been injured in a car accident and so wrote a thing on the importance of seatbelts. I remember part of that involved researching reports on NHTSA [National Highway Traffic Safety Administration] crash tests of kid dummies being thrown through windshields without seatbelts.
- Young: It sounds like Phil came in at a pretty tough time. It was a tough job to inherit.
- Stein: He had a hard--and I think he had a hard time dealing with it. I don't have good, strong recollections of Phil's period of leadership. Again, that's something--Mary Lester worked really closely with him, and she'd be a wonderful person [to talk to].
- Young: Do you know much about why Judy Heumann had come in as deputy director and didn't become executive director?
- Stein: No.
- Young: How about Judy? Did you have many dealings with her and her management style, her leadership style?
- Stein: No, I wasn't there when she was the director. We were friends.
- Young: I was thinking of deputy director when she came in in '75.
- Stein: I didn't carry with me any recollections of her as deputy director, except that she was always so busy. She was just a

powerhouse. Her poor assistants worked so hard. Judy was always on the phone, always doing things. Judy Heumann is probably the most active person I've ever met in my life. Just tremendous drive and energy, just runs at ninety miles an hour.

Young: Did that rub off onto the people around her at CIL?

Stein: No, she was in her own sphere. She was like an atom spinning around.

Young: Say more about that. That's really interesting.

Stein: That's just the way I remember her, just that she was always really busy, worked her staff really hard--not in a mean way, but just, I mean, they really worked. There's an attorney in town--Mary Dryovage--I have her on the network list, but if anybody wanted to talk to her, she became an attorney herself, but she was Judy's assistant, who'd be a good person to talk to about Judy.

Young: You mentioned Ed as being very reluctant to say no. Were Phil and Judy better at sort of reining in and tightening up CIL, or was that a problem that--

Stein: I don't remember. I can't speak to it.

Young: Okay. How much do you recall about the board of directors? Where did they fit into the leadership and direction of CIL?

Stein: I can't speak to it. No recollection. You know, saying this--my memory of it is so vague. The two words that pop into my head is, like, rubber stamp. That was my sense of what they were. It's my sense now of what they were, but I can't really recall that much directly. I think they kind of were a rubber stamp outfit because they weren't part of the day-to-day operations. They probably just trusted whatever happened.

Young: So the executive director had a lot of leeway.

Stein: Oh, yes, absolutely.

Young: You talked a bit about funding. Is there anything you'd like to add about the problems that funding posed?

Stein: No, that was all.

Young: How about the Friends of CIL?

Stein: I don't think they existed when I was there.

Young: Okay.

Stein: That was later.

Pivotal Moments in the Center for Independent Living's History

Young: As you look back over your tenure or even outside of your tenure, what do you see as the most pivotal moments in CIL's history? Are there a few things that really stand out to you?

Stein: I think historically the most pivotal thing is CIL's move from a very small organization on University Avenue to a huge organization on Telegraph, Ed's getting funding for similar programs all over the state and for CIL becoming a national model. I mean, what's pivotal is the whole fact--and that's what I talk about when I talked at CIL's anniversary program--is that now it's easy to take for granted what we have today in terms of independent living, disability access, and disability rights. The reality is that what CIL did was to change centuries-old attitudes and worldwide attitudes, literally, centuries-old attitudes about people with disabilities and what they were capable of achieving, and to carve out an opportunity for people to accomplish things, was just incredible. It's an incredible, incredible accomplishment for a little grass-roots organization to have had.

When I talked at the Berkeley Historical Society dinner, I was introducing speakers, and I carted out some stamps that were disability-related stamps from the period, and there was this stamp from a year or two before Ed--right around the time Ed was in college. And where I'd first used the stamps was I gave Ed's mother a set of these with some narrative. I made a little tiny book of them. But when Ed was in college, the stamp said, "Hope for the Crippled," and the hope for the crippled was some guy getting out his wheelchair and walking. That was the goal. And, like, a year or two after 504, there was a stamp with the words, "Disabled doesn't mean unable," with a guy sitting in a wheelchair looking through a microscope. This community in CIL had a lot to do with that change, which was an incredible change.

So the pivotal moments of CIL were--whenever that moment--I don't know if it's a moment, but the process of its becoming a national model, the process of the impact of the changing attitudinal barriers, and operationalizing stuff to create accessible communities and to put it out of the arena of charity into the arena of civil rights. It changed, what they called a paradigm change, the whole context of how people with disabilities

are viewed, not just attitudinally but in terms of the law and protections people have.

I mean, CIL had so much to do with that in terms of carving up 504 and 504 becoming the model of ADA. Certainly, 504 was a key pivotal moment for the people at CIL in terms of what--team-building is a mild word to say for it--but just total empowerment, of empowerment for people with disabilities, taking control over their futures. So certainly the 504 was.

DLRC. The founding of DLRC, which became DREDF, was certainly key--that transition from the issue of independent living, living independently, to recognizing that people can't really live independently if--you know, they can feel as independent as they want, but if they can't get off their curbs or can't get jobs or can't get into transit, mass transit, what's the good of it? So that translation from independent living to access to disability rights, to me, is sort of a key issue.

Young: You've just made an allusion to DLRC. That was one of many spin-off type organizations that came out of CIL.

Stein: Yes, that was born at CIL and incorporated on its own.

Young: Right. Others, like CTP [Computer Training Project], the K.I.D.S. Project [Keys to Introducing Disabilities in Schools], and BORP [Berkeley Outreach Recreation Program, now called Bay Area Outreach Recreation Program], stayed more within--how did all these get started? Were these from various grants, like you said would come in--

Stein: Yes.

Young: --and then sort of go off on their own?

Stein: Well, a lot of people, I can't speak specifics--wanted to go off on their own--because they wanted to be autonomous. I mean, there was CTP, there was WID, there was BORP. Part of it speaks to a wonderful climate for fostering, being open to new ideas and new programs. All these things were very important, and all these agencies have had important national and international impacts on their own.

Young: Did you have a sense that the various programs were carefully integrated and making their missions coincide? Or did it seem more like each organization was kind of doing somewhat of its own thing?

Stein: No, I mean, it was all working together. It was all part of independent living. It all was a different piece. It all was, like, bringing in deaf services, blind services.

Young: In the In-House monthly, Judy made a reference to a reorganization in 1976. It was kind of cryptic. We couldn't quite tell what she meant. Do you recall that?

Stein: No.

Young: Okay. It sounded like it might have been a significant event.

Stein: 1976. Let's see. I started in '74. CIL probably--I think--'75--don't know. They--I think it was probably around '76 when they brought in Sally Swenson, I believe, as the person who did the design. It was just a shell when we moved in. And did some physical, structural design and work there. And at a later point they re-did the back offices. The whole back area of CIL used to be a warehouse space.

You know, I'll tell you my very earliest recollection of CIL was 1971, which was three or four years before its founding. I lived on Channing Way, and there was my next-door neighbor when I was in graduate school--had a little MG and he had to get his MG repaired, and we were going on some outing, and so I went with him to the MG place, which was 2539 Telegraph. And so we pulled up into the driveway, and the window was a window to the left where you turned in his papers and got his MG fixed. It was an MG repair place for foreign autos before it was CIL. And that was the garage area, where wheelchair repair was. It was a perfect match because what it was was the area where they repaired cars. They had these lifts that would lift up the cars, and they were able to use that for vans modification. It was all built in, the hydraulics. So that was my first recollection. My first knowledge of CIL was really 1971.

Young: I didn't know that it was a repair shop.

Stein: Yes, that's what it was.

CIL's Demographics: Race, Gender, Sexual Identity, and Disability

Young: That's very interesting. I'd like to talk a little bit about demographics. I'm especially interested to hear both among staff and among clients, what was the representation of people's disabilities, racial and ethnic minorities, women, people who were

openly gay, elderly persons? Can you talk a bit about those sorts of representations?

Stein: Yes. If I miss some of the groups, let me know. You can keep track.

Young: Okay, I will.

Stein: There was a black driver; maybe one or two. Mary would remember. Mary remembers people better than me. There were blacks on staff; there were black clients. I'm sorry, I can't remember the names. Kitty would remember the names of some of these people. My memory for names isn't good, I'm afraid. Joyce Jackson was someone, black woman. I believe Ron Washington worked there at that time. I remember a black driver, also a woman who was one of the dispatchers in the transportation department.

There were a lot of women. One thing that really stands out about the independent living/disability rights movement is all the women who were prominent in it. And what stands out from--there was a video documentary called "The Sixties." And they were talking about all these different movements and spin-off movements from movements in the sixties out into the seventies. And what you see--and what you see when you look at this documentary and in movies like "Woodstock" from that period--it's all males, all the men up there doing the leadership, and women's liberation didn't really start until '69, and I don't think was really accepted for a number of years later. Our Bodies, Ourselves. Sisterhood Is Powerful. Sisterhood Is Powerful was 1968, '69, I think, one of the first breakthrough things.

So that what stands out is that the 504 demonstration, it's all women leadership. It was very unusual for a political movement to have such a powerful presence of women leadership. Similarly, at CIL there's a lot of women leadership and there were a lot of out gay women who were employees at CIL.

Young: Would you say there were more women than men among the staff?

Stein: I don't know. You'd have to look at the staff roster and count. But there were a lot of women. There were a lot of women in prominent leadership roles throughout the history of CIL, and in very important backup administrative roles.

Young: How do you account for that? I think that's a really interesting observation.

Stein: And lesbian women, too. Part of it is, like, the gay women who were there brought their friends; it was a warm, welcome place for

people, and they were openly gay at a time when there weren't a lot of people being openly gay. You know, it's sort of an odd theory, but at the time I felt it. To state it might be to overstate it, but I think CIL was a movement of mobility-impaired people who were spinal cord injured, and I--this is a sensitive area to talk about.

I think that perhaps severely disabled men are not a threat to women, psychologically or sexually or whatever. It's also my sense that severely disabled men frequently feel disempowered and project a sense of not powerfulness because they've had a lot of their starch taken out of them. And the whole thing about being a man in our society and bravado and stuff is a big part of psychology that plays into being a man with a disability or a spinal cord injury who have lost their sexual functioning. And I think that perhaps gay women were in a situation where they weren't threatened by powerful male leadership.

Young: So they were able to excel better then.

Stein: So you had situations where people in Mary Lester's position or Joan Leon's position were able to have a tremendous amount of power in a way that other male-female boss-secretary relationships--I think it was probably a non-traditional kind of relationship in the terms of power and authority that women who were, quote, "behind the men" assumed and maintained. It's kind of a provocative thought, I guess, but I mean, I remember feeling it at the time very strongly.

Young: Fascinating.

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Stein: Yes, what we were just talking about with the tape recorder off, and I'll talk about a little more about, is the whole issue of disabled men perhaps feeling emasculated. I think one important postscript to that discussion has to be that at the time of the start of the independent living movement there really wasn't a disability rights movement. All there were were these horrible old attitudes that people had internalized about themselves. So that's what people were riding in on, so that there were still a lot of breakthroughs to be made in terms of sexual identity and disability, I think. The whole issue of disability pride--it was just beginning. Hopefully, that would be less of an issue today.

Young: I know one of the things that was important in the course of the ADA was the encouragement and fostering of meetings to write discrimination diaries and to come to the self-awareness of instead of only looking inward at yourself and feeling like

there's something wrong with you, to have a consciousness-raising experience that society has attitudes and structures that are discriminatory.

Stein: There's no question.

Young: And that self-revelatory process, I think, is really important.

Stein: And Staring Back does that really nicely. Are you familiar with it?

Young: Only recently. I'd like to see a copy.

Stein: But Staring Back does that. I think one thing that people with disabilities getting together at 504--it's embarrassing to talk about sex, right? But just the fact that the relationships that came out of CIL and 504 and the awakenings there were.

Young: I was actually impressed by that, in reading some of The Independents. Pretty frank talk about sexuality, which I thought was a good and healthy thing. That may be because of the physiological issues involved that people with disabilities in an organization like CIL were maybe more forthright and progressive in terms of talking about that than the general public was.

Stein: As in many areas, I think that CIL was on the cutting edge of that issue as well.

As for the general issue, I don't know. I can't speak to it. I'm not a person with a severe disability. I know that people with severe disabilities, there are some real privacy issues--being naked in front of other people. Being physically cared for by other people. There's a lot less privacy. So I don't know about the impact of that in terms of being maybe more open about things.

You know, looking back, in retrospect, I think that's one other way that Ed Roberts was a role model during his years at CIL, because there he was--this really severely disabled guy who could barely move, and I think he had to spend just about all of his time at home in an iron lung, and breathing with a respirator anywhere else--there he was, with a very nice girlfriend, and then a wife (same person), and then a son. I think that that probably did have a big impact on people, even though it wasn't discussed like that, it was out there nonetheless.

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Stein: Getting back to your question of why people came to CIL, I think--also something--originally, my first draft of my CIL speech included this, and this is where Kitty said, "Oh, you can't say that! I don't know if that's even true." But I think that a lot of people were feeling disenfranchised in the late sixties, early seventies, for a lot of reasons, and I think that a lot of the people without disabilities or without visible disabilities gravitated toward CIL, when you asked what Mary Lester meant when she talked about flotsam and jetsam.

Young: You mentioned gay women. Were there gay men as well, or was it more among women?

Stein: Scott Luebking, who started the computer training project, was a gay man. When he wrote an article for The Independent, "Getting There Was Half the Fun," talking about sex and being disabled, it was mutually decided between him and Jan to not emphasize that, not be out in that article that he was gay or that the sex he was talking about was gay sex. When I asked Scott--last year, I said, "You know, Scott, I've always been curious. Was that because CIL told you not to put that in about being gay, or was that your choice?" And he sort of said it was kind of his choice that he wanted to have appeal to a general audience, so I mean, he wasn't out in that article.

Keeping in mind, I think gay liberation didn't really pick up steam, it was sort of present in a very small way in 1969, '70, when I first came out here, but it was a small group of people. It was a new idea, and it wasn't even big. There was a gay liberation group on campus.

Young: In terms of people with disabilities, it seems from what you've said and some of the things that I've read that the greatest representation was among physically disabled, especially spinal cord injured people. Is that your impression?

Stein: No, that's what it was. It was the whole thing of what CIL came out of the Disabled Students' Program was severely--the original concept was for people with severe disabilities.

Young: Was there a conscious attempt to try to broaden that to being more inclusive of all types of disabilities? Or were other people with disabilities simply not coming for the services?

Stein: Well, you had--deaf people had their own deaf culture. Deaf people had never been part of mainstream America. They had been part of deaf America, with their own schools, their own culture. Don't consider themselves to have a disability; they consider themselves deaf. So it's always been good when there has been a

cross-over bridge onto disability rights. When Dale Dahl came to CIL--had a tremendous impact in terms of bringing deaf services--I don't know if he brought deaf services or whether deaf services brought him, but in any case, it was a good thing when that happened.

Coalition became very, very important for 504 and continued on into ADA [Americans with Disabilities Act], and I think that was a time when--and also on the whole issue of children and education, which CIL got very involved in very early on, with the Disability Law Resource Center's parents education project with Arlene Mayerson, Pam Steneberg, and Diane Lipton. Disabled kids and their right to an education being an issue. So coalition really became important. Whether it was important before--I'm not saying it wasn't, but it took on key importance at 504, people standing together.

Young: How about elderly persons? One thing that stuck out to me in the In-House monthly was it noted for March 1976 there was something in the realm of 1629 rides given on the van service and 420 or so of them were for elderly persons. That just seemed like a really high number to me. I always associated CIL with young people.

Stein: No, can't speak to it. It's interesting. It's nice that that survives in the In-House.

Young: Okay.

Stein: I should talk about the In-House monthly because it was a nice thing. That was something that I started, I think because I had the feeling that CIL was growing very rapidly from this small little group of people I worked with on University Avenue to a huge thing with a lot of different departments. So I wanted to have something where different departments could know what we're all doing, so it could be a community organization. And so--we didn't have a xerox machine in those days or not one that was high capacity in any case. I don't think we did. I had worked over at Stiles Hall with the adolescent program, Napa Hospital. Fran Lindsey was the secretary there and the power in that office, and so I called and asked if I could use the mimeograph machine, and she said sure. And so I would have the mimeographed master and typed it up on the typewriter and then bring it over there and have it cranked out. And at Stiles Hall, let us use her machine to do that. That's how that got published.

Young: How long did it run?

Stein: Well, I didn't know. It looked like, what? A year and then it became the membership news. I don't know what happened after that or if there were no more issues. Who knows?

Young: It's hard to tell.

Stein: Hard to tell. All that remains are the ones that I have.

Young: One other question about this issue of demographics. What did the diversity contribute? You know, having minorities, having women as well as gay persons. Did that do something special for CIL?

Stein: Well, I think having gay women, strong gay women in staff member roles had a lot to do with the strike and the outspokenness of the staff in confronting the administration.

Young: A lot of assertive people.

Stein: A lot of assertive people. I mean, it was just a community and to say what was the impacts, it was just, like, well, I don't remember racial conflicts; I don't remember subtle, hidden racial conflicts. Maybe the black staff people would, but I don't.

Young: Were people generally receptive to openly gay people as part of the staff? Was that welcomed?

Stein: It was never an issue.

The Center for Independent Living and Local Politics

Young: How about political or ideological issues? Where did people stand on the political spectrum?

Stein: Well, you know, I think one thing where CIL didn't do much was in terms of local organizing. With the notable exception of the time that CIL successfully prevailed at the city council in opposing the Berkeley fire chief's trying to disallow CIL's computer training project locating on an upper story of 2020 Milvia.

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Stein: CIL, as you say--where they've done a bad job--CIL has been interested in organizing nationally, internationally. Never got it together in terms of the city, so that you had the city of Berkeley, the birthplace of the independent living movement and the cradle of disability civilization, didn't have a transition

plan for ADA. They're just working on it now, you know, seven years later. They were great on curb cuts, but as far as political organizing, CIL didn't organize politically. It always blew me away when CIL finally allied with a political organization, with Michael Winter's allying himself with the most conservative elements in the Berkeley political structure, the ABC/BDC [All Berkeley Coalition/Berkeley Democratic Club], which was just basically for rich people in this community. I think because Michael is somebody who identifies with the power structure, but the whole issue of--

I mean, I used to talk to Mike. I'd say, like, "Michael, you know, BCA [Berkeley Citizen's Action] is the organization that helps poor people, and most people with disabilities are poor." But he never quite got it. You know, he was going to kiss up to the people looking out for the big business, big developer interests.

Disability is a funny issue politically because--you know the ADA came out during the Bush-Reagan administration, right? What's that about? Partly it's about people's myths about Democrats, but partly it's about that disability really crosses over and impacts everybody and every family.

Young: I got the sense, though, that CIL was more rooted in the Democratic party.

Stein: Oh, there's no question. But the group that Michael Winter was allied with was the All Berkeley Coalition/Berkeley Democratic Club, but for Berkeley, they were the Republicans. It's true. It's absolutely true. They were people that were looking out for the interests of big business, big developers; they were for people cutting social services. At the time of Prop. 13, it was the Berkeley Democratic Club/All Berkeley Coalition which used Prop. 13 as an opportunity to totally gut nine great social services agencies, community services, and a lot of the really affirmative sorts of programs. But then, as now, disability as an issue is unique in its ability to appeal to both sides of the political spectrum, unlike other rights movements. But what has always been clear to me at least is that when push comes to shove, people with disabilities are better served by the agenda of the left.

Young: It seems like it was also sort of a socialist-Marxist presence at CIL.

Stein: Well, I mean, Kitty comes from real leftist roots, and Hale does. But what the extent of that impact is--I don't know that that's "roots of CIL" or just the presence of these people, just like

there were gay people there. That's the way I always saw it. I mean, Kitty would always be hawking her Daily Worker or whatever it was. It wasn't Daily Worker. Something. She'd always try to get you to buy a paper for a quarter. But it wasn't--it was a separate agenda.

That being said, there's no question that the independent living/disability rights movement that was born and grew up at CIL was of course a direct ideological outgrowth of the black civil rights movement and UC Berkeley's Free Speech Movement, as was the case with other rights movements of the sixties and seventies. So yes, of course, the disability rights movement has its ideological underpinnings in leftist philosophy. Even so, the fact remains that the independent living movement was carving out its own new territory on its own terms. I guess I tend to think of the founders of the independent living movement more like pioneers than "leftists."

II VOLUNTEER WORK, PERSONAL INTERESTS, MARRIAGE AND FAMILY, AND DREDF

[Interview 2: January 21, 1998] ##

Comparisons of the Center for Independent Living and the Disability Rights Education and Defense Fund

Stein: I was assistant to the editor of Access, DLRC's national disability rights newsletter. I helped write articles, research articles. I also did some photographs for them. At that time, I was gearing up. I was a photographer. I was also working actively with Grassroots newspaper at that time. At Grassroots I did a lot of writing, editing, and photography.

Young: Grassroots was the name of an organization?

Stein: Grassroots was the newspaper, was a local community newspaper I worked with for ten years.

Young: Was it a disability newspaper or all sorts of stuff?

Stein: It was sort of a community newspaper. It was sort of a leftist community newspaper. It was a volunteer newspaper collective where we all did--traded off being editor, you know, and doing layout. Did layout.

Young: Did you feel like the missions of DREDF and CIL coincided really well, or were they kind of pulling off in different directions, do you think?

Stein: That's really a good question for Mary Lou or Bob Funk. At the time--well, I didn't really finish what I was saying what I did at DLRC, DREDF. I did a resource guide on employment for people with disabilities. Actually, it was a resource guide on employing disabled people. It was targeted to employers and rehab specialists. I did that under Debby Kaplan. At that time, DREDF had already moved to San Pablo Avenue.

My sense--and, again, for the real answer I'd go to Mary Lou or Bob--but my sense was that there was a recognition that the civil rights component was very separate from the independent living component, and it was real appropriate for it to be in a separate organization. And I think there were some funding or political issues that made that have to be that way as well.

Young: How about the administrative and management styles of the two organizations? Would you describe it as one more successful than the other in terms of managing an organization and fulfilling a mission?

Stein: Well, to the extent that DREDF was able to keep from going down the tubes and CIL was not--CIL didn't completely go down the tubes, but it really came as close as you could come without the final flush. So, in that sense, I think DREDF has been more successful. I think that, at least from the sense of the community and from what I see, I think DREDF now has been somewhat more successful in what it has done than CIL has been able to do in terms of--I don't know.

Let me sort of tell you what I'm getting at here. I think that if you use the community, what the community feels as a standard, there's probably equal frustration with both organizations. But my belief is that the feeling toward DREDF is somewhat less founded, based on the lack of understanding what DREDF's role is and mission in the community, in the sense that what DREDF does--DREDF tends and always has tended to want to do class-action cases that expand the definition of the law, that extend people's understanding the law, that extend the envelope of what the law covers. And that's what DREDF has been about.

It has not been a law center that helps everybody who has been discriminated against because of disability, so that in the sense that when people go into a restaurant and are kicked out because of their disability and DREDF doesn't take the case--or whatever--that people say, "Oh, DREDF isn't there for the community." So whereas, in fact, that's not DREDF's role, to be a mill for disability rights cases.

Young: And more of a national perspective.

Stein: They have a national perspective. Or even if they do cases locally--do local cases, but they are cases that have a national impact, like the Amtrak case or the diabetes case and have to do with--DREDF's resources are limited and that's what DREDF chooses to do, whereas I think with CIL, a lot of the frustration is that the core services that should be provided aren't being provided in a way that is helpful to people. Their notoriously poor attendant

referral service and things like that. So that when I was saying there is dissatisfaction on the part of the community toward both organizations, the dissatisfaction toward CIL might be somewhat more well-founded.

It also goes to the issue of what are the roles of CILs? Are CILs the best places to be providing services now that we have come this far? These are issues that Mary Lou has talked about, has expressed concern about to me. Just philosophically, what is the role of the independent living centers in the nineties or in the next few decades?

Young: What do you think?

Stein: I think that before people with severe disabilities can be really equal, there has to be some sort of economic parity that doesn't exist, and major changes have to be made in the system of how benefits are made available and distributed. If there is going to be a major arena of cutting-edge, political activity in the next ten or fifteen years, that's where it's going to be, to really allow people with disabilities to be equal citizens. And I think that's not something that's going to happen at the independent living centers.

Founding of the Berkeley Historical Society, 1978

Young: Tell me a little bit about the Berkeley Historical Society. What was your role, and what was the mission?

Stein: Well, 1978 was the city of Berkeley's centennial. I was already somebody very interested in Berkeley history and was an avid collector of Berkeley things, as I talked to you a little bit about earlier, so that when there was a city of Berkeley centennial exhibit at Live Oak Arts Center, I was on the committee to help put that exhibit together. After that exhibit ended, me and I don't know, three or four other people said, "Now's the time." There was stuff that we'd gotten together for the exhibit; there's resources; there's people we know who are interested in Berkeley history. And so we set up an initial planning meeting.

A year before, even, I had sent away for papers of how to incorporate. Basically, we just got it started. In the last five years, the Historical Society got a museum site, so we finally have a museum. I don't know exactly what the Historical Society's mission statement is, but it basically has to do with studying Berkeley's history and making that history available. I'm not on

the board anymore. I dropped out after--about three months ago. And I wasn't on an entirely straight run through. I was off for about six or seven years in the middle, maybe more or less. I don't know. But I was on the board until very recently.

But I was actively involved in the mechanics behind getting the exhibit there, the twenty-five years--I don't remember the exact name of the exhibit now. Berkeley Leads: Thirty-Five Years of Disability Rights. Something like that. It was a really nice exhibit. I think it was the first exhibit in the country to really focus on disability rights history.

Young: This was at the museum?

Stein: It was at the museum. And where that came from was that we were able to--I was the chair of the 504 committee, and I was able to rustle up, out of that, somebody, Carol Krezman and Linda Rosen, to be the docents of that exhibit and gather the stuff. It was sort of the offshoot of the 504 celebration that we were able to get that rolling and make that happen.

Chairman of the 504 Celebration, 1997

Young: Tell me a bit about the 504 celebration. You said you were chairman of the committee?

Stein: Yes. I'd been involved in the tenth anniversary of 504. We had a little get-together at a local church. But for the twentieth anniversary, thought it would be nice to have a big deal around it, especially because we had really lost a lot of friends and leaders in the disability community over the past five or six years. In the last year and a half, two years we'd been particularly hard hit--with Greg Sanders, Mary Ann Hiserman, Lynn Kidder, Ed Roberts. And Phil Draper died shortly before that.

I felt and I do feel that CIL, the people who go back that far, as far as I do, that we are a family in a very real sense. I don't know if I said it on the tape. Berkeley in the sixties and seventies was full of family refugees, people who were leaving home and had stuff they wanted to get away from, from their homes. And so, for me at least, I feel a real kinship with the people I worked with in the early days of CIL, a real bond. And the only time I was seeing this family was at memorial services. So I wanted us to have a party.

Also, I was very conscious of this being an opportunity and creating an opportunity out of this to have video oral histories. That was always a goal early on. As long as we were getting people together, to have part of that program that night be videotaping people. Which we did. We ended up videotaping fifty-five people about their experiences at the sit-in.

Young: Where are those now?

Stein: Joni has them, Joni Breves.

We also put together a video documentary and a radio documentary of 504, and a very good book. [Available in the Disabled Persons' Independence Movement Project Archives] There's a lot of backlash against ADA now. It was a real good opportunity to get out there with what disability civil rights is all about and to reaffirm for people who lived through it and to let people know who didn't. And in that sense, I think the event was a tremendous success. We had about six or seven hundred people come out.

We met every month. There was a committee of about twenty people, more or less, came to every meeting. We represented a lot of organizations locally, pretty much. We met for over a year. We hired JPD Communications to do the actual event organization--they were the people who pulled together the logistics and everything. We were able to get a tremendous site to have it in. We raised about \$85,000, which is a tremendous amount for a volunteer effort. So we were able to produce a radio documentary, a video documentary, put together a really tremendous book that Sharon Bonney worked on. The whole thing was a great success.

The feedback we got was just great in terms of people with disabilities who didn't even know--many of the younger people had no concept of the 504 demonstration or why it was important. And I think a lot of people with disabilities--younger people grow up, taking stuff for granted, and it's really important to understand the roots of all of this, to understand that 504 and other civil rights laws aren't things that Hubert Humphrey or their government, whatever, thought would be a good idea and handed to them on a silver platter. But this is something that people worked on and struggled for and that there's a need to continue that.

So it's a really tremendous thing. It's something that I'm real proud of, to have thought of it and organized it and chaired and carried it through. That's something I feel real good about in my life.

Photography Work

Young: You should.

I want to hear a little bit about your photography. How did you get started in that? And how did that fit into your work with disability?

Stein: Well, it goes, actually, pre-photography, to when I was working on The Independent. There was a Vista class in news writing. I was already a good writer, but I took the class. It was in newspaper writing. I took the class, and the first assignment I did an article, "Hearst Strip Sold--Neighborhood Organizes." It was a good newspaper story, and I gave it to Doug Brown, who worked at the wheelchair repair--van modification. He worked at van modification at CIL.

He worked with Grassroots newspaper. And so they put it on the front page of the newspaper. It was a good story; it was timely and important, about how Vista Community College wanted to use the Hearst Strip, and people wanted it to be a park at the time. It didn't seem there was a chance that Vista would lose it. But there was a lot of organizing the neighborhood did, and it did end being a park, where BART runs, under the tracks.

But out of that I began working with Grassroots on a more regular basis and became real politically involved in local development issues in the community. I started wanting to illustrate my stories with photographs, and that was really the beginning of my photography. I also started taking a lot of photographs around CIL for DLRC. Also for Grassroots, I began covering the disability demonstrations. I took some very nice pictures. A lot of my pictures became part of the exhibit at the Berkeley Historical Society disability history exhibit. A lot of nice pictures of parents and children with disabilities, also demonstrations and other people.

Young: Was it ever part of your employment at CIL? Were you getting paid to do photographic work, or these things you just sort of did on your own, on the side?

Stein: It was always on the side. They used some of my photographs in Access for some of the demonstrations. I wasn't paid anything extra. I was just on the staff and they needed some photographs.

But my photography, I did have a sort of separate career for about ten years. I was doing a lot of free lance. I did the photographs for the city manager's office for the annual reports

for the city of Berkeley. I did catalog photos and personnel photos for UC Press. My picture of Judy Heumann was the one that Ms. Magazine used in "Eighty Women to Watch in the Eighties." Nice picture of Judy.

I had hundreds and hundreds, literally hundreds of photographs of mine that appeared in local, regional, national press sources. I liked photography. I was good at it. I never felt like it was a calling in any sense. I was never able to--free lance meant that I would get a lot of work and then no work for months at a time, and then some work, and then a lot of work, and then no work. After I got married and had a family, I couldn't really--you can't live like that, especially in the Bay Area where it costs so much. So I sort of dropped my photography.

I did an awful lot of political work in the seventies and eighties around land-use issues. I was on the Landmarks Preservation Commission for about seven years. I was chair of it for a couple of years. I wrote the city of Berkeley's Nonresidential Demolition Ordinance and carried it through and got it passed. It was a thing to ensure public hearings before, an opportunity for public input, before commercial buildings were knocked down.

I also got a very important section of the zoning ordinance reinstated after it was knocked out, which would have allowed residential apartment owners to turn their property into commercial property. That was able to really save hundreds and hundreds of apartment units for low-cost housing. That's another good thing I did, a legacy of mine.

So I was very active in land use, development issues, throughout the seventies and eighties.

Young: I need to interrupt you a moment. On the photography, did you do all your own developing?

Stein: I did. I did my own darkroom work.

Young: Do you have still all the originals of the photographs you took? Are those saved?

Stein: Yes, I have the photographs. I'll show you some before you leave. I've got a batch here just because they were ones that were returned from the history exhibit.

Marriage and Family, 1986

Stein: My life changed a lot when I got married and had a family.

Young: And that was when?

Stein: I got married in '86, and my daughter Emily was born in '89. I never had a full-time job until I was forty. Before that I always worked three-quarters time. My apartment was \$125 a month. All my work at CIL--one thing to talk about in terms of CIL--and Mary Lester can tell you about this, is the tremendous number of part-time employees and how few full-time employees there were, played in partly to disability issues and whatever; but for me what it played into was I had a lot of time to do a lot of political things, go to a lot of meetings, sleep late. But I wasn't able to do any of that when I had a family.

Also, I didn't choose to continue volunteering because I had spent many, many thousands of hours doing volunteer stuff.

Young: You just couldn't afford to do that anymore.

Stein: Couldn't afford to do that. I did those many thousands of hours of volunteer stuff in lieu of building a career for myself.

Work on ADA Hotline at DREDF since 1993

Young: Can you tell me a little bit about your current activity at DREDF?

Stein: Sure. I began working at DREDF in 1993, in November of '93. The U.S. Department of Justice funds an ADA Hotline, where we provide national telephone information to people about their rights under Titles II and III of the Americans With Disabilities Act. I'm the manager of the ADA technical assistance unit. There is a staff of two people, we get clerical support from DREDF. Paul Church and I work together, and we answer phones.

We get between 800 and 1,000 calls a month. A lot of information referral on disability issues. The numbers are phenomenal in terms of the number of calls we handle. In the five years since I started working there, I've talked to over 20,000 people, giving information referrals. That's a lot of people. A lot of information and referral, a lot of information about ADA.

Young: Is the ADA working, from your estimation?

Stein: Whenever people call on the phone, I never answer that. I just tell them what the ADA is and what their rights are and obligations. I know that the world is a lot better place with ADA than without it. I know that there--if, in asking the question, people mean, Is there still discrimination, you have to say, Well, of course. That's why there was the need for a civil rights law. Is the Fair Housing Act working in the sense that there's still discrimination in housing, against people of color?

I think there's a lot of backlash against the ADA, which is inevitable in any civil rights issue because the bottom line, at heart, is that the ADA goes against what people feel and what people feel comfortable feeling about people with disabilities. But that's why there's the law.

Young: Ken, I've really appreciated your comments. Is there anything you'd like to add or talk about? Final words?

Stein: Coming back to DREDF, just speaking personally, has given my life a sense of continuity that for a number of years I felt I had lost. In a sense, coming back home to people who I worked with a long time ago. I'm very, very proud of the important work that DREDF has done, and I'm very proud and feel very happy to have been a participant and a player in a political and social movement that has literally changed millions and millions of lives. It's been exciting living through almost every phase of the movement for disability rights, independent living, disability access, in that I worked at CIL and Access California and DREDF. I feel like I've been a witness to a whole lot of history and known a whole lot of really important people who made a tremendous impact on the world. That's been an exciting thing, to have lived through that together, to have shared in the growth and development of that movement.

Young: I would think so. Very good. Thank you.

Addendum

[The following was added to the transcript by Mr. Stein after his review of the transcript.]

Stein: In reading over the transcript of my interview, I think that the question might arise, "So how come I've stayed involved with the consumer-based disability rights movement for over two decades?" Although I have never really identified myself as a person with a disability, the fact is that I have some pretty severe immune

deficiencies that have impacted my life, at times quite dramatically. In spite of that, I think that my continued involvement in disability rights issues has primarily resulted from happenstance--one thing leading to another. Nonetheless, just for the record . . .

My mother had a very difficult pregnancy. From what we know now, perhaps I had a twin who died in the womb. For whatever reason, there was a lot of bleeding throughout the first trimester and I flunked three pregnancy tests. The treatment to prevent a miscarriage included over forty injections of various combinations of the hormone corpus luteum, and D.E.S. While there has been a lot of research in regard to D.E.S. daughters and cervical cancer, only recently has there been attention paid to D.E.S. sons, many of whom have turned out to have serious immune system problems. Whether or not that is the reason, I do.

In 1969, I received a medical deferment from the armed services, in part due to my allergies, which at that time filled up three single spaced columns on an 8 1/2 by 11 inch page. I can only wear cotton clothes, I have never been able to use any scented cleaning products or been able to be around people with perfume. I get asthma from a number of things in the natural and man-made environment, and cannot be around dust, mold, new paint (for several days) or new carpet (for several weeks or longer) without suffering severe bouts of sinusitis, bronchitis, and/or asthma. Over the years, I have learned to pretty much avoid the things that make me sick.

The worst problem I have had is with secondhand tobacco smoke. My tongue and the inside of my mouth become very swollen from even the slightest exposure; the swelling eventually gets bitten into and I end up with a sore and swollen mouth for from two to three weeks.

When I worked at CIL's Disability Law Resource Center [DLRC] some twenty years ago, at a time when people still smoked indoors, I was given a special office of my own--a small brick alcove separated from the other offices by the library. We named the space "Stein Hollow," from which I issued a semi-periodic comic newsletter called "The Hollow News." At the time, there was really no awareness that this was a "disability" issue--just my "allergies." In fact, several years ago, when I ran into an attorney who used to work at DLRC, she said, "Oh, yes, I remember you--you're the one who was always complaining about cigarette smoke."

Because of the smoke problem, up until ten years or so ago, I had lived a pretty isolated social existence, as there was

virtually no place I could go in public without triggering the toxic reaction I suffer from tobacco smoke--restaurants, movies, parties, buses, social events, pretty much anything. And so, for about twenty years of my adult life, I simply stopped going places entirely. It is only since the late 1970s with greater awareness about the dangers of tobacco smoke and the passage of local and state laws, that things have turned the corner. Even though we now take smoke-free environments for granted, throughout the 1960s and 1970s people were free to smoke pretty much anywhere--banks, grocery stores, government offices, anywhere.

As a consequence, I suffered a good deal of shame and embarrassment about my situation over the years, and only since the passage of the ADA have I even come to think of myself in the least respect as being honorably "disabled."

Whereas other disabilities require that accommodations be made to the physical environment, mine requires that people change their behavior. Because other people are not bothered by the things I am bothered by, I have frequently been regarded as a complainer, even by my own family, who used to repeatedly put pressure on me to go places with them where they and I knew that I would get sick as a consequence. Even with the passage of the ADA, EI is not something to brag about.

I have spent a great deal of my life feeling like something of an oddity, and in spite of all I know, I think that I still regard it as a reflection on myself personally. Beyond that, I am not, and would never claim to be, severely disabled. In spite of the fact that the ADA has adopted a rather broad definition of disability, I understand as well as anyone that the independent living movement originally came about in order to provide opportunities for participation by persons with severe disabilities.

So . . . does my disability have anything to do with my sticking with the movement for the past twenty-five years? I don't think so, but I thought that I should bring up the issue just for the record.

CIL 25th Anniversary Dinner 10/30/97

Remarks by Ken Stein, Manager DREDF ADA Technical Assistance Unit

I worked at CIL from 1974 to 1982, as CIL's first Public Information Coordinator and as Assistant Editor of The Independent, and later at CIL's Disability Law Resource Center, which became DREDF.

People often talk about CIL as an "it", forgetting about the many people who've made the organization tick, and of the interplay between those people and the success of the movement.

For a variety of reasons, CIL's early staff members were people who could all identify mightily with the idea of independent living. As Mary Lester described our early days, "I remember the enthusiasm and energy for challenging the system. Knowing that we were all on the verge of something big -- undefined, unknown, but very exciting."

Because of its goals and vision, CIL attracted talented and committed people from a wide variety of backgrounds. For example . . .

Phil Draper -- who so skillfully juggled CIL's being an important grass-roots community-based organization, at the same time that it was becoming a national model and powerful voice of the newly-emerging disability rights movement.

Greg Sanders, a brilliant analyst of complex governmental regulations

Gary Rowen, who'd learned wheelchair repair by fixing his brother's wheelchairs

Kitty Cone, a community organizer from the midwest, who came to CIL one day to have her wheelchair repaired, and stayed on in the movement for the next 25 years

Don Galloway (the head of R&D) and Jan McKeown (the Editor of the Independent) who raised everyone's consciousness about blind issues

Lynn Kidder, who had been an attendant, and who in her writing, eloquently articulated CIL's Mission

Hale Zukas -- a red diaper baby who, working with access specialist Eric Dibner, used his political skills to begin ramping the entire city of Berkeley

and many many others . . .

What's clear to me is that the success of the independent living/disability rights movement is not so much a history of heroes and lone wolves as it is a history of inter-dependence, community and connectedness.

The Disabled Students Program itself grew directly out of the bonds formed at the Cowell Residence Program. [U.C. Berkeley's Physically Disabled Students Program /PDSP, later renamed the Disabled Students Program, preceded CIL and was the model on which CIL was based.] From the outset, there has been a commitment to the principle that CIL would be an organization of and for all disability groups working together in coalition. And it was always a primary goal of Independent Living that people with disabilities would participate fully in the life of the community.

Likewise the relationships that were forged out of a common commitment to the civil rights struggle, which would attract so many others to CIL and to Berkeley. It was in the context of these relationships that a political agenda was defined and has been continually refined and redefined over the past 3 decades.

From almost the earliest days of CIL, the media has referred to Berkeley as a "Mecca for the disabled." What they usually mean by this is that Berkeley is a place that people flock to because of its reputation as an accessible city. But we all know that the meaning runs much deeper -- that Berkeley in general and CIL in particular is a Mecca in the sense of its being the birthplace and spiritual center of the independent living / disability rights movement. It's no accident that organizations like CTP, DREDF, BORP, Through the Looking Glass, and WID -- organizations that have had major national and international impacts in their own right - - are programs that originated at CIL or were begun by former Staff.

In the final analysis, what our community did was something utterly phenomenal. Because what it did was to transform literally millions of lives and centuries-old attitudes, not only in this country, but throughout the world -- from people being viewed as objects of charity and rehabilitation, to people worthy of self determination willing to fight for and achieve their human and civil rights.

I am very proud to have participated in this wonderful history, as it was, and as it continues into the future.

TAPE GUIDE--Builders and Sustainers of the Independent Living Movement in
Berkeley, Volume I

INTERVIEW WITH HERBERT LEIBOWITZ

Date of Interview: November 17, 1998

Tape 1, Side A	1
Tape 1, Side B	9
Tape 2, Side A	18
Tape 2, Side B	27

INTERVIEW WITH MARY LESTER

Interview 1: January 22, 1998

Tape 1, Side A	34
Tape 1, Side B	44
Tape 2, Side A	55
Tape 2, Side B not recorded	

Interview 2: March 10, 1998

Tape 3, Side A	64
Tape 3, Side B	73

Interview 3: April 28, 1998

Tape 4, Side A	82
Tape 4, Side B	90
Tape 5, Side A	99
Tape 5, Side B not recorded	

Interview 4: May 7, 1998

Tape 6, Side A	101
Tape 6, Side B	109

INTERVIEW WITH BETTE MCMULDREN

Date of Interview: October 8, 1998

Tape 1, Side A	123
Tape 1, Side B	133
Tape 2, Side A	144
Tape 2, Side B	155
Tape 3, Side A	165
Tape 3, Side B not recorded	

INTERVIEW WITH KENNETH STEIN

Interview 1: January 16, 1998

Tape 1, Side A	174
Tape 1, Side B	187
Insert from Tape 2, Side A	195
Resume Tape 1, Side B	196
Tape 2, Side A	199
Tape 2, Side B not recorded	

Interview 2: January 21, 1998

Tape 3, Side A	202
Tape 3, Side B not recorded	

INDEX--Builders and Sustainers of the Independent Living Movement in
Berkeley, Volume I

- AC Transit. See Alameda-Contra
Costa Transit District
Access, 202, 207
Access California, 210
acquired immune deficiency
syndrome, 28
ADA. See Americans with
Disabilities Act
AFB. See American Foundation of
the Blind
affirmative action, 54, 83, 86,
102, 108, 151-152
AIDS. See acquired immune
deficiency syndrome
Alameda County, 54, 64-65, 69,
83, 84
Alameda-Contra Costa Transit
District, accessibility of
buses, 43, 98
alcoholism, rehabilitation for,
5-7
Alliance for Technology Access,
116-117
American Foundation of the Blind,
153
Americans with Disabilities Act,
143-144, 180, 192, 195, 198,
200, 206, 209-210, 212
Anderson, Norman, 40-41, 101, 102
Antioch College West, 52-54
Apple Computers, 114, 117
architectural barriers and
accessibility, 20, 38-39, 42,
62, 128, 158, 162, 165
attendants, 20, 35, 56, 62, 100,
150, 157, 185, 187; referral,
39, 40-42, 91, 106, 136, 162,
185, 187, 203-204

BART. See Bay Area Rapid Transit
Bates, Tom, 60-61

Bay Area Outreach Recreation
Program. See Berkeley Outreach
Recreation Program
Bay Area Rapid Transit, 43, 98,
176, 178
BEH. See Bureau of Education of
the Handicapped
Bendix, Paul, 96
Berkeley, city of, 54, 64-65, 69,
82, 83, 86, 98, 99, 102, 199-
200, 207-208; politics, 200
Berkeley Fire Department, 38-39,
69, 199
Berkeley Historical Society, 182,
191, 204-205, 207
Berkeley Outreach Recreation
Program, 80, 183, 192
Berkeley Police Department, 16
Berry, Don, 94, 100, 101, 112
black power movement, 9
Black Panthers, 91, 108
blind services, 40, 41, 65, 85-
86, 88, 101, 134, 153-155, 176,
184, 193
Bodine, Joanne, 149
Bonney, Sharon, 206
BORP. See Berkeley Outreach
Recreation Program (now Bay
Area Outreach Recreation
Program)
Brand, Jackie, 114, 116
Brand, Judith (Shoshana), 115
Brand, Steve, 114-115
Brean, Edna, 16
Breslin, Mary Lou, 189, 202-204
Breves, Joni, 79, 206
Brown, Doug, 207
Brown, Edmund G., Jr. ("Jerry"),
39, 64
Bureau of Education of the
Handicapped, 89, 131
Bureau of Indian Affairs, 5

- Califano, Joseph A., Jr., 144
- California Association of the Physically Handicapped, 96
- California State Department of Rehabilitation, 14, 21, 25, 39-40, 46, 48, 51, 57-59, 64, 65-66, 74, 76, 77, 80-81, 84-85, 92, 95, 96, 102-103, 106, 109-110, 127, 133, 136, 143, 148-150, 186, 188
- CAPH. See California Association of the Physically Handicapped
- CARF. See Commission on Accreditation of Rehabilitation Facilities
- Caulfield, Cathrine, 101
- Center for Independent Living, Inc., 13, 16-17, 20-21, 26, 28, 35-118 *passim*, 126-164 *passim*, 167, 176-204 *passim*, 207, 209; board of directors, 62, 70-76, 79, 87, 89-90, 101, 134-135, 190; Community Affairs Department, 101-102; dissatisfaction with, 47, 70-77, 89-90, 93, 161, 185-188, 203-204; Foundation for Independent Living, 55; Friends of CIL, 52, 76, 155, 159, 190; grants, 21-24, 40, 44-46, 52, 54, 57-59, 61, 64-69, 74, 76, 84-85, 96-97, 104, 109, 112-113, 131-138, 148-149, 159, 161, 184-186, 188, 203; mobility training, 40, 101, 153; paralegal project, 130-131, 138, 146; peer counseling, 21-22, 40, 44-46, 91, 134, 153, 178, 179; Urban Institute Comprehensive Needs Study of Persons with Disabilities, 176-177, 182. See also Computer Training Program, wheelchair repair
- CETA. See Comprehensive Employment and Training Administration
- Chandler, Elissa, 28
- Chavez, Phil, 45
- Children's Defense Fund, 131
- Church, Paul, 209
- CIL. See Center for Independent Living
- civil rights movement, 12, 24-25, 104-105, 107-108, 160. See also black power movement
- Civil Rights Act, 143-144, 210
- Clarke, Arlene, 91, 108
- Cole, Chuck, 72, 74
- Columbia University, Teachers College, guidance laboratory, 3-4, 9
- Coming Home*, 158, 162
- Commission on Accreditation of Rehabilitation Facilities, 130, 165-166
- community organization, 2-3
- Comprehensive Employment and Training Administration, 69, 84, 137
- Compton, Tony, 91
- computer technology for persons with disabilities, 177. See also Computer Training Program
- Computer Training Program (now Computer Technologies Program), 39, 40, 55, 77-80, 109, 192, 199
- Cone, Kitty (Curtis), 40, 62, 98, 101-102, 103, 181, 189, 194, 200-201
- Council of State Administrators of Vocational Administration, 48-49
- Cowell Hospital residence program. See University of California, Berkeley
- cross-disability inclusion, 57, 60-61, 85-86, 88-89, 91, 107, 116, 125-126, 152-156, 158, 184, 193-194, 197-198
- CSAVR. See Council of State Administrators of Vocational Administration
- curb-cuts/curb ramps, 16, 62, 98, 102, 192, 200

- Dahl, Dale, 88, 136, 141-142, 198
 Davis, Terri, 79
 DCARA. See Deaf Counseling
 Advocacy and Referral Agency
 DCCG. See Disabled Children's
 Computer Group
 deaf services, 57, 60, 76, 88-89,
 134, 136, 141-142, 152-154,
 158, 160, 163, 184, 193, 197-
 198
 Deaf Counseling Advocacy and
 Referral Agency, 141
 Department of Education, U.S.,
 26, 28
 Department of Health, Education
 and Welfare, U.S., 12, 26, 44-
 45, 144
 DeSimone, Tony, 17
 developmental disabilities, 57,
 89, 154-155, 164
 D'Angelo, Nancy, 41, 56, 102,
 125, 142-143, 183
 Dibner, Eric, 46, 178
 disability, and education, 11-14,
 38, 51, 52-55, 68, 99, 105,
 114-116, 125-126, 132-133, 138,
 162, 198
 disability, and employment, 4,
 13-14, 20, 28, 54-55, 74-78,
 85-87, 102-103, 105-106, 108,
 134, 149, 179, 187, 192, 202,
 209
 disability, and housing, 86, 108,
 110, 128-130, 163, 165
 disability, and marriage, 112,
 196
 disability, and race, gender, and
 poverty, 85-87, 89-91, 108,
 151-152, 193-200
 disability, attitudes toward, 13-
 14, 44-45, 89, 92-93, 104-105,
 111, 127, 141, 158, 160-161,
 167, 176, 178, 179-180, 185,
 191-192, 194-196, 204, 206
 disability culture, 111
 disability, establishing
 independence, 15-17, 20, 29,
 44-46, 61, 92, 100, 136, 142-
 143, 149, 160-161, 185, 191-192
 disability, experiences with
 discrimination, 108, 142-143,
 151, 158, 161, 195-196, 203,
 210
 disability, family response and
 reaction, 107, 114-116, 198
 disability, identity, 13-14, 28-
 29, 105-106, 136, 142-143, 160-
 161, 183, 195, 206
 disability, international, 126,
 140
 disability, perceived hierarchy,
 57, 85-86, 141, 155-156
 disability rights, as a civil
 rights issue, 12, 24-25, 61,
 104-105, 107-108, 138, 143,
 158-160, 191-192, 201, 203,
 206, 209-210
 disability rights movement, 180-
 181, 191, 194-195, 198-200,
 209-211; Berkeley's advantages,
 56, 88, 90, 98-99, 110, 201
 Disability Rights Education and
 Defense Fund, 110, 137-138,
 178, 192, 202-204, 209-210
 Disabled and Blind Action
 Committee of Northern
 California (DBAC), 62-63, 102
 Disabled Children's Computer
 Group, 77, 114-116
 Disabled Law Resource Center, 54-
 55, 79-80, 85, 110, 138, 177,
 178, 186, 192, 198, 202, 211
 DLRC. See Disability Law Resource
 Center
 Dowda, Russ Cooper, 179
 Draper, Phil, 35-36, 38, 41, 43,
 47-53, 55, 56, 59-60, 62 65,
 67-69, 71-74, 79, 87, 90, 94,
 98, 100, 101, 104, 107, 109,
 111-112, 132, 133, 135, 144,
 151-152, 156, 178, 189, 190,
 205
 Draper, Sharon Amato, 111-112
 DREDF. See Disability Rights
 Education and Defense Fund
 Dryovage, Mary, 190
 Duggan, Catherine, 45-47, 112,
 127-128

- Ellison, Lucy, 11
 Engstrom, George, 23-24
 environmental disability, 210-212
 Essert, Paul, 9
 ethnic minorities, discrimination
 against, 2-3, 5-6, 9, 86, 108.
 See also affirmative action
- Fewell, Carol, 35, 36, 37, 38,
 129-130
 Foisie, Frank, 128, 129
 Fonda, Jane, and *Coming Home*,
 158, 162
 Free Speech Movement, UC Berkeley,
 10-11, 110, 201
 Frieden, Lex, 24
 fundraising, 51-52, 60, 61, 80-
 81. See also Center for
 Independent Living, grants
 Funk, Robert J., 138, 202-203
 Fussy, Tom, 39
- Galloway, Donald, 21, 40, 41, 62,
 101, 184
 Gallup Indian Community Center,
 4-7
 Galvin, Don, 165-166
 Garrett, Jim, 12
 gay and lesbian community, 88,
 89, 194-195, 197, 199, 201
 Gensler, Steve, 114-115
 GLAD. See Greater Los Angeles
 Council on Deafness, Inc.
 Goodwyn, Karen Topp. See Topp,
 Karen
 Grassroots, 202, 207
 Greater Los Angeles Council on
 Deafness, Inc., 141
 Grimes, Ruth, 101
 guide dogs, 37
- halfway houses, Bonita House, 175
 Harveston, Dominic, 52-54
 Herring, Larry, 52, 85
 Hessler, John, 13, 14, 15-16, 18,
 27
- Heumann, Judy, 14, 17-18, 19, 26-
 28, 48, 50, 56, 59-62, 67, 71,
 83, 88-90, 95, 98, 105, 107,
 109-110, 125, 129-152, 154-157,
 159, 165-166, 186, 189-190,
 193, 208
 HEW. See Department of Health,
 Education and Welfare
 Hiserman, Mary Ann, 205
 Hofmann, Steve, 125, 142
 Hoover, Bob, 5-6
 Hull House, Chicago, 8
- IBM, 40, 77-78, 109
 IHSS. See In-Home Supportive
 Services
 In-Home Supportive Services, 62,
 110
 InDelicato, Jeanne, 102
 independent living centers, 17,
 23, 26, 60-61, 80-81, 91, 94-
 97, 102, 108, 110, 116, 147,
 163, 187, 191, 204
 independent living concept, 15-
 21, 24, 26, 40, 44-46, 60, 80,
 94-95, 107, 147, 177, 179, 181,
 187, 191, 192, 195, 199-201;
 research on, 23-25
 Independent Living Conference,
 48-49
Independent, The, 41, 101, 177,
 179, 184, 196, 197, 207
 Internal Revenue Service (IRS),
 CIL's problems with, 69-70,
 73, 93
 International Center for the
 Disabled (formerly Institute
 for the Crippled and Disabled),
 125-126
- Jackson, James, 101
 Jackson, Joyce, 194
 Jacobs, Abe, 4
 Jacobs, Leo, 141
 Jacobson, Denise Sherer, 56
 Jacobson, Neil, 40, 66, 77-79,
 109, 125, 142

- Jauregui, Joanne, 158-159
 Jeffers, Jim, 131
 Jimenez, Ramon, 136, 148-149
- Kailes, June, 95
 Kaplan, Deborah, 73, 87, 202
 Kellogg Foundation, 117
 Keys to Introducing Disabilities
 in Schools Project, 54-55, 89,
 132-133, 138, 192
 Kidder, Lynn, 41, 52, 71, 99,
 100, 101, 103, 105, 111, 135,
 139, 159, 205
 KIDS Project. See Keys to
 Introducing Disabilities in
 Schools Project
 Kirshbaum, Hal, 45, 52, 53, 159
 Koppel, Ted, 179, 183
 Krezman, Carol, 205
 Krones, Janice, 36, 40, 88, 102
 Kurtz, Lee Ann, 79
- labor unions, 73-77, 82, 89, 113
 Langdon, Larry, 13
 Leech, Peter, 16, 84-85, 88, 102,
 128
 Leibowitz, David, 3
 Leibowitz, Herbert, *Int.* 1-29
 Leibowitz, Mickey, 1, 3, 4, 11
 Leng, Henry, 143, 148
 Leon, Joan, 17, 20, 22, 28, 39,
 41, 49-52, 58, 65, 74, 93, 104,
 133, 136, 189, 195
 Lester, Mary, *Int.*, 34-118; 132-
 133, 136, 137, 139, 181-182,
 188, 189, 194-195, 197, 209
 Lewis, Gordon, 138
 Lindsey, Frances, 198
 Lipton, Diane, 198
 Lomax, Brad, 91, 108
 Luebking, Scott, 40, 77-78, 109,
 197
- MacGregor, Bill, 68, 101, 185
 Martin, Douglas, 17
 Mayerson, Arlene, 198
- McDonald, O.J., 128-129
 McEwen-Brown, Janet, 41, 101,
 139, 184, 185, 197
 McKeever, Earl, 187
 McLaughlin, John, 45
 McMuldren, Bette, 49, 60, 65, 67,
 84, 95, 99, 105, *Int.* 123-167
 Medi-Cal, 41, 54, 101, 110, 179
 media, 27, 51, 62, 145, 156-159,
 178-179, 180
 Medicare, 179
 Medsger, Betty, 111
 Mobility International, 183
 Moore, Frank, 114
 Moyer, Jeff, 146, 153, 162
 Ms. Magazine, 156, 208
- National Association for Mental
 Health, 7
 National Federation of Settlements
 and Neighborhood Centers, 7-9,
 29
 National Federation of the Blind,
 153
 National Highway Traffic Safety
 Administration, 189
 National Institute on Disability
 Research and Rehabilitation,
 28
 Navajo Tribe, 5-7
 New York University, program in
 rehabilitation counseling,
 125-126, 142
 NFB. See National Federation of
 the Blind
 NIDRR. See National Institute on
 Disability Research and
 Rehabilitation
 No Pity, 183
 Northwestern University, 34-35
- O'Hara, Susan, 14
 Oakland, city of, 69
 Okuno, Ken, 41, 101
 Owen, Mary Jane, 155

- Pachovas, Michael, 79
 Paley, Martin, 65
 paratransit, 98
 Peace Corps, 11
 Pechen, Jim, 85, 130, 138, 146
 Perlman, Itzhak, 154
 Perotti, Linda, 45
 Perrotti, Caesar, 28
 photography, 207-208
 Physically Disabled Students'
 Program, UC Berkeley, 12-16,
 27, 56, 79, 110, 176, 197
 Pimental, Al, 154
 Plunket, Camille, 101
 Proposition 13 (June 1978), 65,
 200
 prosthetic devices, 22-23
 psychiatric disability, 184
 Public Policy and Independent
 Living (PPIL) Research and
 Training Center, 28
- Reagan, Ronald, 10-11
 rehabilitation, in Arizona, 164-
 166; in general, 3-7
 Rehabilitation Act of 1973, 18,
 93; amendments to, 18; San
 Francisco 504 sit-in, 62, 95,
 144-146, 156, 180, 191-192,
 194, 196, 198, 205-206
 Rehabilitation Services
 Administration, funding, 16,
 18, 64, 65, 67, 84;
 rehabilitation engineering, 22-
 23, 25; research and training,
 11-25 *passim*, 29, 164
 Reswick, Jim, 23
 revenue sharing, 64-65, 97-98
 Roberts, Edward V., 6, 13, 14,
 16-19, 21-27, 28, 35-37, 39-43,
 45-53, 57-59, 64-67, 69, 74,
 77, 81, 87, 91, 95, 98, 101,
 102-104, 107-110, 112, 127,
 140, 177, 179, 182, 183-187,
 189-191, 196, 205
 Rogers, Judi, 114
 Rosen, Linda, 205
 Rowan, Gary, 37, 58, 66, 101
- Rowan, Jack, 71, 140-141
 RSA. See Rehabilitation Services
 Administration
 Rusk Institute, 126
 Ryan, Barry, 21
- San Francisco Foundation, 65, 159
 Sanders, Greg, 40, 101, 140-141,
 205
 Santos, Dick, 130, 155, 156, 160
 Schechter, Diane, 183
 seatbelt legislation, 178, 189
 sexist attitudes, 40, 87, 90.
 See also women's issues
 Shaefer, Paul, 11
 Sheets, Paul, 9
 sign language, 141-142, 158
Sisterhood Is Powerful, 194
60 Minutes, 27, 156-157, 179
 Smith, Dan, 153
 social work, in Los Angeles, 1-3;
 in Washington, D.C., 124; study
 of, 1-4, 15
 Social Security Disability
 Insurance, 140-141
 SSI. See Supplemental Security
 Income
Staring Back, 196
 Staros, Tony, 22-23, 25
 Stein, Emily, 209
 Stein, Kenneth E., *Int.* 169-212
 Steneberg, Pam, 198
 Stoddard, Sue, 21, 45
 Stubbs, Miriam, 19
 Supplemental Security Income, 40,
 56, 75, 110, 134
 Support Center, 47, 108
 Swenson, Sally, 193
 Switzer, Mary, 19
 Sygall, Susan, 183
- Taylor, Judy, 112
 Taylor, Lynnette, 112
 Taylor, Rafe, 74
 technology, adaptive, 22-23, 114-
 117, 177
 Thompson, Al, 4

- Thornton, Marilyn, 87
 Topp, Karen, 77, 150
 transportation, access to, 98,
 142, 149-151, 178, 192, 198;
 Great Pumpkin, 43-44;
 Volkswagon bus, 36, 40-41, 43,
 101, 102
 Traub, Joe, 22-23, 25
 Trier, Peter, 71, 134-135

 United Cerebral Palsy (UCP), 96-
 97
 University of California,
 Berkeley, 35, 51, 56, 82, 99,
 106, 109, 110, 128, 174, 176;
 Cowell Hospital, 16; funding
 problems, 11; Social Welfare
 Extension, 9-11; Stiles Hall
 Project, 175, 198. *See also*
 Free Speech Movement,
 Physically Disabled Students'
 Program
 University of California, Los
 Angeles, 17
 Uzeta, Ray, 96

 vans, modification, 54, 57-58,
 66, 98, 149-150, 193, 207
 Velton, John, 77
 Veterans Administration,
 Rehabilitation Engineering,
 22-23
 Vietnam War, 35, 37, 99, 160
 VISTA. *See* Volunteers in Service
 to America
 Vocational Rehabilitation,
 Department of. *See* California
 State Department of
 Rehabilitation
 Volunteers in Service to America,
 76, 88, 133-134, 141, 153

 Walker, Lisa, 131
 Washington, Ron, 194
 wheelchair design, 22-23, 57-58,
 66
 wheelchair repair, 37, 39, 40,
 41, 54, 66, 76, 98, 101, 106,
 134, 136, 151, 156, 183, 193,
 207
 wheelchairs, use of, 36-37, 88,
 94, 98, 112, 127-128, 141, 147,
 152-154, 183
 White House Conference on Persons
 with Disabilities, 130-131
 WID. *See* World Institute on
 Disability
 Wiebe, Carol, 40, 101, 153
 Williamson, Dale, 15-16, 20-21
 Willsmore, Herb, 13, 15, 151
 Winter, Michael, 96, 162-163,
 186, 200
 women's issues, 90, 194-195, 199.
 See also disability and race,
 gender, and poverty
 World Institute on Disability,
 28-29, 177, 192
 World War II, 2
 Wright, Pat, 53

 Zimmerman, Don, 131
 Zukas, Hale, 16, 62, 82, 98, 101-
 102, 176-178, 200

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Regional Oral History Office

Disability Rights and Independent Living

Movement Oral History Series

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Susan O'Hara proposed the idea of an oral history of the disability movement to ROHO in 1982, and currently serves as consultant historian and interviewer for the DPIM project. She was a resident in the Cowell program for disabled students in the summer of 1971 [a wheelchair user from polio in the 1950s] and became director of the program when it moved from Cowell Hospital to the university residence halls in 1975. She served as director of the umbrella organization, the Disabled Students' Program, from 1988 to 1992, and was chair of the campus Committee to Remove Architectural Barriers during that time. She has long been active in the disability community, including national and state associations on higher education and disabled students.

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In August 1998 Mr. Young left the project to become associate director of disability outreach for the White House Office of Public Liaison.

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